DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

Doctorate in Clinical Psychology: Main Research Portfolio

1) Critical Review of Literature: Adding insult to injury: failure to recognise domestic abuse in people with disabilities: a systematic review; 2) Service Improvement Project: Increasing staff confidence and implementation of trauma therapy skills; 3) Main Research Project: Exploration of body perception and body dissatisfaction in young people with intellectual disability.

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Award date:
2016

Awarding institution:
University of Bath

Doctorate in Clinical Psychology: Main Research Portfolio

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May 2016

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Abstracts

Main Research Project

Background: People with intellectual disability (ID) are more likely to be overweight or obese compared to their peers, which fuels the need for effective healthy weight management programmes targeted at this population. In order to inform such programmes, more evidence is needed relating to how people with ID perceive their bodies.

Method: This study uses qualitative and quantitative methodology to explore body perception and body dissatisfaction in 40 young adults with ID compared to 48 individuals without ID. The Stunkard Figure Rating Scale was used to assess how participants perceived themselves, how they would like to look, and how they conceptualised underweight, healthy-weight and overweight. This rating scale was shown to be a valid and reliable measure when used with this population.

Results: Results show that young adults with ID tend to hold positive beliefs about their bodies. Females with ID are likely to perceive their bodies to be smaller than they are and neither males nor females report a desire for an altered body size. The results also suggest that individuals with ID understand what is meant by 'overweight', 'healthy-weight' and 'underweight' although these concepts are qualitatively different compared to those held by people without ID. Furthermore, individuals with ID are unable to apply these body size categories to themselves.

Conclusion: It is vital to consider these findings when designing healthy weight management programmes for people with ID. These individuals will need to be supported to understand how concepts of body size apply to themselves before they can move on to make positive choices about their weight management.

Service Improvement Project

This service improvement project followed the Model for Improvement framework (Langley et al., 2009), comprising two 'plan-do-study-act' cycles. The aim of this project was to support NHS staff without specialist psychological therapy skills to provide phase one trauma work to service users with complex post-traumatic stress disorder (C-PTSD). Semi-structured focus groups were used to elicit staff views on what would be helpful to facilitate this work (n= 8). The findings from these focus groups informed the production of a resource pack that staff could use to assist phase one of trauma focussed work, which included psycho-education, stabilisation and emotion regulation training. Questionnaires were used to assess the amount of phase one trauma based work completed and the perceived level of confidence in staff before and after the introduction of the resources. A total of 16 participants provided ratings before the introduction of the resources and nine participants provided ratings following the introduction of the resources. Findings indicated that the use of phase one trauma skills by staff without psychological training had either stayed the same or increased following the introduction of the resources and staff confidence ratings were higher when staff had access to the resources compared to before the resources had been made available. These findings demonstrate that recovery from C-PTSD can potentially be facilitated by developing resources for staff to use with service users.

Critical review of the literature

There is incontrovertible evidence that domestic abuse is a highly prevalent phenomenon with wide reaching clinical and health implications. Individuals with disabilities are at significant risk of domestic abuse victimisation yet their experiences are often poorly documented and understood. This systematic review builds upon the ecological model of domestic abuse in people with disabilities, which was first outlined almost two decades ago by Bonnie Carlson. At a micro-system level, factors associated with domestic abuse in people with disabilities that were not previously reported by Carlson included being married, being younger, having a low income, being unemployed, having lower levels of education and having unmet health needs. At a meso-system level, additions to the ecological model for domestic abuse in people with disabilities included increased isolation from other carers and restrictions in reporting abuse resulting from the immediate social environment. Finally, additional

macro-system factors included a lack of responsiveness by services, which, in part, appears to be influenced by an inadequate understanding of how domestic abuse manifests in people with disabilities. The definition of domestic abuse is examined to explore how this fails to capture the experiences of people with disabilities.

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Acknowledgements

Main research project and Literature review

I would like to thank Dr Cathy Randle-Phillips who supervised me for my main research project and literature review. Cathy has provided continuous support throughout both projects and encouraged my passion for working with people with intellectual disability. In relation to my main research project only, I would like to thank Dr Claire Delaney and Dr Ailsa Russell for helping to formulate the research question. I am especially grateful to Becky Osborne, Neale Fox and Tony Willner for facilitating recruitment and the students who took part, without whom this research would not have been possible. Finally, thank you to Sophie Thomas for all of her hard work throughout data collection and the qualitative data analysis process. Her reliably calming presence, motivation and integrity helped ensure the success of the data collection days.

Service Improvement Project

Thank you to my supervisors Dr Maria Loades and Dr Chris Gillmore. Chris was key to every phase of the Service Improvement Project, from identifying a need of the service to focus the project on, facilitating recruitment of participants, and also advising on the write up stage. Maria was a huge support for helping develop the project design and provided invaluable personal support throughout the research process, which helped to keep everything on track. I would also like to express my thanks to the staff in the Avon and Wiltshire NHS Partnership Trust, who took part in this project.

Case studies

I am grateful to each of the clients who consented to having their cases written up. This demonstrates a huge selflessness in allowing others to learn and benefit from one's own difficult experiences. I also valued the support of each of my placement supervisors in taking time to review the final case studies.

Consultancy project

Thank you to the Avon Forensic Community Learning Disability Team for their conscientiousness and support during the completion of my consultancy project.

Personal

I would like to thank the 2013 cohort for being a constant support during the ups and downs of trainee life and making life on the course manageable. It has been a real pleasure getting to know all you!

Finally, I would also like to thank my boyfriend, Christian. He had no clue what he was signing up to when he agreed to move to Bristol but has been my constant rock throughout the rollercoaster of emotions of this course. Thank you for sticking with me!

Adding insult to injury: Failure to recognise domestic abuse in people with disabilities; a systematic review

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Target journal: Journal of family violence (see appendix A for instructions for authors)

Adding insult to injury: Failure to recognise domestic abuse in people with disabilities; a systematic review

Abstract

There is incontrovertible evidence that domestic abuse is a highly prevalent phenomenon with wide reaching clinical and health implications. Individuals with disabilities are at significant risk of domestic abuse victimisation yet their experiences are often poorly documented and understood. This systematic review builds upon the ecological model of domestic abuse in people with disabilities, which was first outlined almost two decades ago by Bonnie Carlson. At a micro-system level, factors associated with domestic abuse in people with disabilities that were not previously reported by Carlson included being married, being younger, having a low income, being unemployed, having lower levels of education and having unmet health needs. At a meso-system level, additions to the ecological model for domestic abuse in people with disabilities included increased isolation from other carers and restrictions in reporting abuse resulting from the immediate social environment. Finally, additional macro-system factors included a lack of responsiveness by services, which, in part, appears to be influenced by an inadequate understanding of how domestic abuse manifests in people with disabilities. The definition of domestic abuse is examined to explore how this fails to capture the experiences of people with disabilities.

Key words: ecological model, domestic abuse, disability, victim.

Adding insult to injury: Failure to recognise domestic abuse in people with disabilities; a systematic review

Introduction

Domestic abuse typically refers to a pattern of behaviour that happens in the context of a relationship and is generally perpetrated by a family member or intimate partner. This is associated with significant clinical and health implications (Ellsberg, Jansen, Heise, Watts & Garcia-Moreno, 2008; Mechanic, Weaver & Resick 2008) and encompasses a broad range of behaviours, including stalking, sexual, physical, emotional and financial abuse (Home office, 2013; Office on violence against women, 2007). Estimated prevalence rates of domestic abuse are extremely high, often reaching 70% in some settings (Alhabib, Nur & Jones 2010; Garcia-Moreno, Jansen, Ellsberg, Heise, & Watts, 2006). It is approaching 20 years since Carlson described the presentation of domestic abuse in people with intellectual disability (Carlson, 1997) but, after two decades, these findings have still not been incorporated into a definition of domestic abuse that recognises and validates the experiences of these victims. The following literature review builds on the work of Carlson (1997) to document and define the presentation of domestic abuse in people with disabilities. Similarities and differences between domestic abuse perpetrated towards individuals with disabilities and domestic abuse towards members of the general population will be highlighted. In contrast to the Carlson (1997) paper, this review will also draw on literature from domestic abuse in people with different forms of disabilities, including amongst others physical disability and disability due to mental health disorders. This broader scope has been adopted in order to maximise the potential findings given the limited literature available. People with disabilities of different aetiologies often share characteristics that would be relevant within a domestically abusive relationship, such as social isolation, limited options for escape and a power imbalance between victim and perpetrator. Therefore, it was felt that research findings relating to people with specific disabilities may be generalisable to people with disabilities as a whole.

Research findings have indicated that people with physical and/or intellectual disability are at significant risk of abuse (Brownridge, 2006; Curry, Hassouneh-Phillips, & Johnston-Silverberg, 2001; Young, Nosek, Howland, Chanpong, &

Rintala, 1997) and this abuse is likely to last for longer periods of time compared to abuse towards people without disabilities (Hassouneh-Phillips & Curry, 2002). This highlights the particular need for domestic abuse to be understood in this population.

Carlson (1997) used the ecological model to describe factors that contribute to, or maintain, domestic abuse in women with intellectual disability. This model consists of three separate levels; the micro-system, the meso-system and the macro-system. Briefly, the micro-system relates to individual characteristics of the victim and the perpetrator, such as levels of assertiveness or over-compliance. The meso-system looks more at the individual within their social context, including the quality of their relationships and their communication skills. Finally, the macro-system describes the societal environment in which the abuse takes place, for example, society views of gender roles or of people with disabilities.

At the micro-system level, Carlson (1997) identified several personality factors that predispose women with intellectual disability to being a victim of abuse including having a high level of dependency on others, lacking assertiveness, being overly compliant and having low self-esteem. Women with intellectual disability were said to internalise negative and stigmatising beliefs about themselves and their disability, leading to a sense of deserving abuse. A history of abuse compounded this belief that they were undeserving of a loving and respectful relationship. Carlson (1997) also noted that victims with intellectual disability who had failed attempts to leave an abusive relationship had a sense of learned helplessness. Cognitive limitations were also highlighted as a maintaining factor to abuse as this limited the individual's ability to generate solutions to escape abusive relationships. Many of Carlson's findings mirror what is known about victims of abuse in the general population. For instance, there is an increased risk of domestic abuse in women in the general population who have experienced prior domestic or childhood victimisation (Riggs, Caulfield & Street, 2000). However, Carlson's findings indicate that intellectual disability results in an exacerbation of vulnerability, whereas, in the general population, this increased vulnerability is associated with substance misuse or mental health difficulties as opposed to cognitive limitations (Riggs et al., 2000).

At the meso-system level, Carlson identified social isolation and poor relationships with relatives as maintaining factors to domestic abuse (1997). Abusive relationships were characterised by poor problem solving skills and poor decision making, and a power imbalance between the physically and/or intellectually inferior victim and the dominant perpetrator. Also, women with intellectual disability were often over-protected by their families, leading to a naiveté or ignorance about intimate relationships, which increased their vulnerability to abusive. Carlson also noted the tendency for people with intellectual disability to be overprotected, and lack control in their own lives, which makes them more vulnerable to being trapped in an abusive relationship (1997). Again, Carlson's findings indicate that intellectual disability may exacerbate risk factors that are also found in the general population. For example, The Duluth Model (Pence & Paymar, 1993) is a treatment approach for working with perpetrators of domestic abuse in the general population. This model suggests that men use a number of strategies to increase their power and control in a relationship. This includes controlling social interactions, forcing a women to be subservient to the male's wishes and the male having control over finances. All of these strategies for creating a power imbalance in the relationship are perhaps more easily implemented in relationships with people with disabilities, where a discrepancy between intellectual and/or physical ability already exists.

At the macro-system level, Carlson discussed gender stereotypes that contributed to domestic abuse in women with intellectual disability such as the idea that women should be passive and home bound, whereas men should be independent, aggressive and in charge (1997). The idea of a "good wife", who is compliant and submissive to her husband was also discussed. These gender stereotypes also contribute to domestic abuse in the general population (Pence & Paymar, 1993). Carlson (1997) also noted societal values and beliefs that promote the mistreatment of people with disabilities, including dehumanising stereotypes that depict people with disabilities as dangerous, helpless, diseased or worthless. Additionally, Carlson (1997) summarised research that suggested that, even if women with intellectual disability sought help for domestic abuse, there was a lack of accessible and appropriate services

to support them. There was also a lack of opportunities for women with disabilities to be trained in skills which may help prevent abuse, such as assertiveness, independence and self-reliance.

The ecological model proposed by Carlson goes some way to describe the factors that contribute to, and maintain domestic abuse in people with disabilities (Carlson, 1997). However, these findings only relate to women with intellectual disability, not to people with other types of disability or to men. Also, the domestic abuse discussed by Carlson (1997) is limited to abuse where the perpetrator is an intimate partner. Current research and recent events and have indicated that abuse towards people with disabilities, occurring in their home environment, does not necessarily comply with this traditional idea of domestic violence (Flynn, 2006; Healthcare commission, 2007; Sobsey & Doe, 1991). In 2011, a BBC Panorama investigation revealed serious physical and emotional abuse and neglect of adults with intellectual disability in Winterbourne View hospital, a private hospital in South West England (Undercover care: The abuse exposed). All of the abuse recorded was perpetrated by paid care staff, 11 of whom were subsequently charged with 38 counts of neglect or ill-treatment of people with intellectual disability (Department of Health, 2012). The events that occurred at Winterbourne View Hospital currently fall outside of those defined as domestic abuse because the perpetrators were not family relations or intimate partners. However, the abuse did take place within the victims' home and was characterised by an imbalance of power between the victim and perpetrator, which is consistent with the current understanding of domestic abuse. In addition to differences in perpetrators of abuse towards people with disabilities, research has also identified acts of abuse that would only be seen as abusive if the victim has a disability, for example, removing a battery from a wheelchair, demanding a kiss before assisting with a transfer or the threat of withholding medication (Curry et al., 2001). Again, these abusive acts would not currently fall under the accepted definitions of domestic abuse. It is important to consider whether the domestic abuse referred to in the ecological model proposed by Carlson is sufficient when applied to people with disabilities, or whether the definition of domestic abuse needs to be refined to take into account differences in perpetrator-victim relationships and disability specific abusive acts.

The aim of the following literature review is to consolidate and evaluate research findings in the area of domestic abuse in people with disabilities and to add this information to the ecological model of domestic abuse proposed by Carlson (1997). The strengths and limitations of using this model as a framework for understanding domestic abuse in this population will be discussed. The findings from this review will then be used to consider whether current definitions of domestic abuse adequately capture the individual, interpersonal and societal vulnerabilities associated with abuse in people with disabilities.

Method

Web of Science and PsychInfo were used to conduct a literature search for all peer reviewed, primary research papers, in 'all years', relating to characteristics of victims of domestic abuse AND people with disabilities. Only papers accessible in English were included. Table 1 lists the search terms that were used.

Table 1

Search terms used in the systematic review of the literature

Search term	Variation
Domestic abuse	"Domestic* abus*" OR "domestic* violen*" OR "spous* abus*" OR "spous* violen*" OR battering OR "family abus*" OR "family violence" OR "dating abuse" OR "dating violence" OR "intimate partner abuse" OR "intimate partner violen*" OR "partner abus*" OR "partner violence" OR "maltreatment" OR "marital abus*" OR "marital violen*" OR "marital rape" OR stalking OR "carer abus*" OR "carer violen*" OR "interpersonal control" OR "relational aggressi*" OR "Wife abus*"
Disability	"Intellectual* disab*"OR "learning disab*" OR "mental* disab*" OR "cognitive* disab*" OR "mental* retard*" OR "mental* handicap*" OR "mental* deficien*" OR "cognitive* deficien*" OR "intellectual* development* disorder*" OR "slow learner*" OR "learning difficult*" OR "learning disab*" OR "developmental* disab*" OR "developmental* difficult*" OR "intellectual* impair*" OR "cognitive* impair*" OR disab* OR Idiocy OR "Physical* disab*" OR "physical* handicap*" OR "physical* disorder*"OR "Disable* person*" OR "physical* challenged"

A search of the literature was conducted on 10th October 2014 and yielded 81 results in PsychINFO and 103 results in Web of Science. Duplicates were deleted if the authors and title of the papers were the same. 54 duplicates were identified, resulting in a total of 130 papers. The titles of the remaining papers were read and papers were excluded if they referred to child abuse rather than domestic abuse (43 articles) or did not relate to either domestic abuse or people with disabilities (3 articles). The abstracts of the remaining 84 articles were read and 34 further exclusions

were made to irrelevant papers. Papers were deemed irrelevant if they did not have a focus on both domestic abuse *and* people with a disability. The final 50 papers were read in full and the reference list of each paper was checked for additional relevant papers. This yielded 25 extra papers, which were then evaluated for their suitability in the same way (i.e. first reading abstract, then the full article). Final exclusions were made, resulting in a total of 21 papers that were included in the literature review. Table 2 shows the main reason why papers were excluded.

Table 2

A record of the reasons for excluding papers retrieved from the systematic literature search.

Reason for paper exclusion	Number of papers this applied to
Not a research article (e.g. book, book chapter, book review, thesis, conference abstract, guidelines for working with victims of abuse).	27
Review rather than original paper	7
Not focussed on disability (e.g. participants with post-traumatic stress disorder or physical health problems with no mention of associated disability)	2
Not focussed on domestic abuse (e.g. work behaviour, society pressure on body image, offending behaviour, intellectual disability as a discipline)	4
Not focussed on victims of abuse (e.g. attachment in children of abused parents, perpetrator of abuse, services for abused people)	7
Prevalence study	2
Questionnaire validity	1
Only available in non-English language	1
Insufficient information about disability	1
Unpublished	2

Critiquing the literature

There is a lack of consensus around the benefits of using standard assessment scales when evaluating the quality of literature within a review (Vereenooghe & Langdon, 2013). On one hand, this introduces an objectivity when assessing the

papers, whereas on the other, this could also introduce a bias to the review process as many scales automatically classify certain study types as superior without consideration as to whether such methodology is most appropriate within a given subject area (Zanker & Mallett, 2013). This review will therefore critically evaluate the research included but no numerical score will be assigned to the individual studies. Also, it is often the case that assessment scales are specifically designed to analyse one particular study type, such as case studies or randomised control trials (Centre for Evidence-Based management, 2016; Critical Appraisal Skills Programme, 2016). As this literature review includes papers with several different research methodologies, a novel checklist was developed, which drew on the most relevant assessment criteria available in existing appraisal checklists (Centre for Evidence-Based management, 2016; Critical Appraisal Skills Programme, 2016). A descriptive criteria that does not feature in these pre-existing measures was included that related to the country where the research was conducted. This was included as there may be cultural differences in the way that domestic abuse and disability are conceptualised so it was deemed important to consider the cultural context of each study. The criteria used to describe and evaluate the research were:

Describing the study:

- Did the study address clearly stated aims
- Inclusion and exclusion criteria of participants
- Recruitment approach
- Statistical analysis employed
- Method of study
- Country of study
- Any measures used including the validity and reliability of the measures

Evaluating the study:

- Whether the participants were likely to represent the target population
- If the sample was representative of the target population
- What proportion of the potential sample took part
- Whether ethical approval was documented

- Any other comments, e.g. whether the conclusions went beyond the data available, the neutrality of the study.

Results and discussion

Overview of papers identified.

A total of 21 papers were included in this literature review. They related to people with various forms of disability who experienced domestic abuse. Many papers included participants with different forms of disability whereas other papers focussed on one type of disability. 14 papers referred to people with physical impairments, seven papers related to people with psychiatric/'mental' disorders, seven papers included participants with intellectual disability and four papers related to people with sensory impairments. A further two papers discussed domestic abuse in people with 'emotional disorders', three papers defined disability as having an impairment that limits daily function and one paper included participants with chronic health problems. One paper did not state the nature of the disability that the participants had, although participants were recruited from a service for people with disabilities. Finally, two papers focussed on the views of support staff working in services for victims of abuse. Table 3 provides a description and brief critique of each paper.

Table 3

Systematic critique of the literature

Paper	Method- participants, recruitment, N, statistical analysis	Critique
1) Ballan, Freyer, Marti, Perkel, Webb & Romanelli, (2014)	**Aim**-Examine key demographics and familial, contextual and social aspects of domestic abuse. **Participants and eligibility criteria**- Women with disabilities who received services from Barrier Free Living. All had disability and all had either experienced domestic abuse in the past or currently. Males and transgender individuals excluded. Aged 16 and over included. Physical, psychiatric, sensory or developmental disability included. **Recruitment**- N/A **N-**886 **Statistical analysis**- percentages and chi squared. **Method**- retrospective analysis of case notes. **Country**- USA (New York City) **Measures**- definition of domestic abuse taken from 'New York State Coalition Against Domestic Violence'. Broader than typical definition. No operationalised definition of disability provided. No measure of disability- self report or medical notes used. No measure of domestic abuse- self report.	-Selected individuals are likely to represent the target population. -This sample is <u>not</u> representative of the whole population. This study only looked at the case notes of females. The study also only included people who were receiving services. People who failed to access services may be different. -Ethical approval provided by Columbia University Institutional Review Board.
2) Barrett, O'Day, Roche, Carlson (2009).	**Aim**-1: describe prevalence of domestic abuse in women with disabilities compared to women without disabilities. 2: Examine whether health status and health care access differ between women with disabilities who are experiencing domestic abuse and those who are not. 3: Examine the association between domestic abuse, health status and health care access in women with disabilities.	-Large and representative sample but unknown whether participants are institutionalised or not. -47-60% of potential participants took part.

Paper	Method- participants, recruitment, N, statistical analysis	Critique
	Participants and eligibility criteria-Unclear who participants are. Either institutionalised women in seven states across the USA. However, in the limitations, they state that the survey does not include women who live in an institution. All >=18. **Recruitment**-telephone survey (digit dial). **N**-23,154 women. **Statistical analysis**- Chi square and then logistic regression to control for sociodemographic factors. **Method**: Cross sectional, population based sample. **Country**-USA **Measures**- Behavioural Risk Factor Surveillance System (BRFSS), an annual cross sectional survey. domestic abuse defined as a women answering yes to "has an intimate partner ever threatened you with physical violence?" or "Has an intimate partner ever hit, slapped, pushed, kicked or physically hurt you in any way?" or Have you ever experienced any unwanted sex by a current or former intimate partner?". Disability defined by a participant answering "yes" to the following questions; -are you limited in any way in any activities because of physical, mental or emotional problems?, do you have any health problems that requires you to use special equipment such as a cane, a wheel chair, a special bed, a special telephone?.	**-Other comments:** The BRFSS does not include a measure of emotional abuse. Also, it is not possible to establish who the participants are as there are contradictions in the text. **Ethical approval:** Not stated.
3) Brownridge, (2006).	**Aim**- Organise risk markers for domestic abuse into a framework based on whether they were related primarily to the relationship, the victim or the perpetrator. **Participants and eligibility criteria**-Women aged 15 years and over. In heterosexual relationships. Living married or common law partner at the time of the survey.	-This sample is representative of the target population although there would be a large variation of participants and it is not possible to break this down. Therefore it is not clear what the nature of disability is for each participant.

Paper	Method- participants, recruitment, N, statistical analysis	Critique
	Recruitment- Taken part in the General Social Survey in Canada in 1999. **N**-1,092 people with disabilities and 5,935 without. **Statistical analysis**- Chi square and logistic multiple regression. **Method**- Cross sectional population based. **Country**- Canada. **Measures**- Disability defined according to the WHO or UN definition of disability. Related to having an impairment that limits daily activities. Modified version of the Conflict Tactics Scale was used to measure Male Partner Violence against Women. No details about how this was modified but specific questions were provided.	- This sample is representative of the whole female population but males are not represented at all. -It is unknown what percentage of the potential sample took part in this study -**Ethical approval:** Not stated.
4) Coker, Smith & Fadden (2005)	**Aim**-Not clearly stated. Appears to be to provide a prevalence rate of domestic abuse and explore the association between domestic abuse and disability (mental and physical). **Participants and eligibility criteria**- Women attending family practice clinics, aged 18-65, insured by Medicaid or a managed care provider, was in or had previously been in an intimate relationship with a man for at least 3 months. Disability including physical and mental health problems. **Recruitment**-Interviewed women seeking medical care in two university associated family practice clinics. **N**-1152 **Statistical analysis**-logistic regression analysis. **Method**- cross sectional. **Country**- USA **Measures**- Not clearly described. Modified and adapted measures of disability and domestic abuse.	- It is unclear whether this research relates to the target population. Women with intellectual disability were excluded although no clear details of how this was assessed. Disability was very broadly defined as a series of medical conditions and/or mental health problems. - This sample is only represents those individuals who were eligible to receive medical care. -89.8% of the potential sample took part -**Other comments-** Conclusions went beyond the data available. The authors inferred that past domestic abuse may cause medical problems and that a medical difficulty currently may put someone at greater risk of domestic abuse.

Paper	Method- participants, recruitment, N, statistical analysis	Critique
		However, no longitudinal data were collected and there was no data to represent when the domestic abuse or medical condition started to know if one predated the other. There was also a lack of statistical power for some of the analyses. Only women who have been in intimate male partners included so this excludes homosexual relationships and also other relationships that may occur in a residential care setting. **Ethical approval**: University ethics provided.
5) Du Mont & Forte, (2014)	**Aim**-Estimate the prevalence of different types of domestic abuse. Examine the risk of domestic abuse in relation to severity of Activity Limitations (AL). Examine how social capital factors are associated with domestic abuse. **Participants and eligibility criteria**- Women aged 15 years or older. Current or former partner with whom they had contact with in the last 5 years. Psychological/mental health problems resulting in activity limitations. **Recruitment**-Random digit dialling across the whole of Canada. **N-**6851 **Statistical analysis**- Chi square and various regression analyses **Method**: Cross sectional population. **Country**- Canada	-This sample represents the target population. Participants had psychological/mental health difficulties resulting in activity limitations. - This sample is representative of the whole female population but males are not represented. -61.6% of the potential sample took part. **- Ethical approval**: Ethics board at women's college hospital.

Paper	Method- participants, recruitment, N, statistical analysis	Critique
	Measures-Social capital characteristics (how safe and connected you feel in your community) assessment clearly described but not validated. Domestic abuse assessed using modified measure, although it was not explained how this was modified. This measured physical, emotional, financial and sexual violence.	
6) Hague, Thiara & Mullender, (2010)	**Aim**-to report the needs of disabled women reporting domestic violence and the services available to meet these needs (not explicitly written as an aim in the paper). **Participants and eligibility criteria**-Women with sensory and physical impairments. Diverse age and ethnicity. **Recruitment**- Surveys sent out to local disability services. **N**-126 respondents to survey, 30 in-depth interviews with women with disabilities and 17 interviews with services. **Statistical analysis**- mixed method, qualitative and quantitative. **Method** Cross sectional although some women reported historic abuse. **Country**-UK **Measures**-No details given about the survey or the questions asked during the interviews. Definition of domestic abuse taken from Women's Aid definition.	-This is very similar to the other paper by Hague (2011). It appears they are reporting the same data twice. -Participants are recruited from disability services so are likely to represent the target population but no verification was made. No information on extent of disability. - This sample is representative of the female population but males are not represented. - 39% of the potential sample took part. - **Ethical approval**: Good ethical considerations and approval from ethics board.
7) Hague, Thiara & Mullender, (2011)	**Aim**-develop further understanding of the needs of abused women with disabilities. Investigate the scope of and gaps in services. Identify examples of good practice. **Participants and eligibility criteria**-women with physical and sensory impairments. **Recruitment**- Unknown	-Participants are likely to represent the target population as they have sensory and or physical impairments. However, no measure of disability was used to confirm this.

Paper	Method- participants, recruitment, N, statistical analysis	Critique
	N- Unknown. **Statistical analysis-** Qualitative. Activist approach. **Method**- national survey and wide ranging consultations. Interview schedules. Qualitative. **Country**- UK **Measures**- None. Definition of domestic abuse taken from 'Women's Aid' definition.	- This sample is representative of the female population but males are not represented. -40% of the potential sample took part. **Ethical approval**: not stated.
8) Hahn, McCormick, Silverman, Robinson & Koenen, (2014).	**Aim**-to examine the association between physical and mental health impairments and domestic abuse. **Participants and eligibility criteria**- Adults with physical or mental health impairment. **Recruitment**-multi-stage sampling design to get a sample representative of the US population. **N-**43,093 at time point one, 32,653 at time point two. **Statistical analysis**-Multi-variable logistic regression- clearly described. **Method**- used data from the national epidemiological survey of alcohol and related conditions. **Country**-USA **Measures**- Conflict Tactics Scale used to assess domestic abuse. Physical and mental health impairments assessed using the 'validated Short Form-12, Version 2'.	-It is unclear whether this sample represents the target population as physical or mental health impairment may not necessary mean disability. -This sample is representative of the whole population. - Over 80% of the potential sample took part. -**Other comments**- people with severe physical or mental impairment not included. Missing data was significantly more likely to be from- older, lower social economic status, in poverty, and have physical or mental health impairments. This might bias the findings. **Ethical approval**: Not stated.
9) Hasan, Muhaddes, Camellia, Selim,	**Aim**-Report the prevalence and experiences of women in Bangladesh with disabilities who experience domestic abuse. Not explicitly stated in the text.	-Participants are likely to represent the target population as they have sensory and

Paper	Method- participants, recruitment, N, statistical analysis	Critique
& Rashid, (2014).	**Participants and eligibility criteria**- Women aged 15 and over (although a table said 14), involved in the women's service for recruitment and had been in a relationship. Participants have sensory and physical limitations. **Recruitment**-Through National Council for Disabled Women. Members of rural, urban and slum communities. **N-**226 in the quantitative survey and 16 in depth interviews. **Statistical analysis**-Logistical regression to investigate the association between socio-demographic characteristics and domestic abuse. **Method**- cross section **Country**- Bangladesh **Measures**- Survey and in depth interviews. No further details given so no information about what was included in the interviews.	physical disabilities. However, no further information given. - It is not known whether these participants represent the population as a whole. These women are part of local organisations so may be different to people who are not members of these organisations. Males are not represented at all. - The percentage of potential participants that took part is not stated. - **Ethical approval**: Appropriate ethical approval granted.
10) Hassouneh-Phillips & McNeff, (2005).	**Aim**-describe the lived experience of abuse in the context of society. Describe concerns and meaning of abuse on their emotional, social and physical wellbeing. Recommend abuse assessment and intervention strategies. **Participants and eligibility criteria**- Women aged 19-60 with physical disability. People with intellectual disability excluded. No description of what physical disability meant. **Recruitment**- Flyers, word of mouth and snowball sampling. **N-** 37 **Statistical analysis**-thematic analysis. **Method**- qualitative. **Country**- Unknown. **Measures**-no measures used.	-It is unknown whether this sample represents the target population. "More or less severe disability" is referred to but no information is provided about what that means. - The percentage of potential participants that took part is not stated. -This sample only represents women, not men. -**Other comments**: The quotes didn't back up the data so findings went beyond the data available. **Ethical approval:** unknown.

Paper	Method- participants, recruitment, N, statistical analysis	Critique
11) Hickson, Khemka, Golden, & Chatzistyli, (2013).	**Aim**- To report the perspectives of support professionals working with people with disabilities. **Participants**- Support staff in domestic violence/ sexual assault services and support staff in intellectual/developmental disabilities services. **Recruitment**-Attendees at regional workshops were invited to complete a survey. **N**- 55 intellectual disability support workers and 16 abuse workers. **Statistical analysis**- t-tests and frequencies reported. **Method**- cross section. **Country**-USA **Measures**- Survey not described in any detail. **Eligibility criteria**- None.	-These participants are not representative of the target population. They are support staff rather than people with disabilities. - The percentage of potential participants that took part is not stated. **Ethical approval**: Appropriate ethical approval granted.
12) Lightfoot & Williams, (2009).	**Aim**- Several aims, clearly stated. All related to people's experiences of gaining help for domestic abuse. **Participants and eligibility criteria**- Participants had to work for an organisation that provided some sort of domestic abuse services, advocacy, or information to black people with disabilities. **Recruitment**- Service providers for people with disabilities. **N**-19 **Statistical analysis**- Thematic analysis. **Method**; Two focus groups. GroupSystem software so people could answer anonymously within a group and the answers would come up live. **Country**- USA **Measures**- Structured group questions although no further information was given about what these questions were.	-These participants do not represent the target population. - The percentage of potential participants that took part is not stated. **Ethical approval:** Not stated

Paper	Method- participants, recruitment, N, statistical analysis	Critique
13) Nosek, Foley, Hughes, & Howland (2001)	**Aim**-Answer the question: what type of abuse experienced by women with physical disabilities are directly related to their disability. **Participants and eligibility criteria**-Women with physical disability that limits mobility or self-care, between 18 and 65, no cognitive impairments or mental health problems that would limit their ability to answer the questions. **Recruitment**-Recruited from independent living centres. **N**-439 people with disability. Control group of 421 also collected but unsure of whether this data was included at all. **Statistical analysis**- Qualitative **Method**- qualitative- analytic induction and constant comparison described by Glaser and Srauss (1967). **Country**- unknown **Measures**- Survey, not fully described. Domestic abuse clearly defined.	-Selected individuals are likely to represent the target population. -It is unknown whether this sample represents the population as a whole. This research only incudes women with physical disability and this is not clearly defined. Males are not represented at all. -45 % of the potential sample took part. -**Other comments:** Very few quotes to back up information that was reported. **Ethical approval**: Not stated.
14) Nosek, Hughes, Taylor, & Taylor, (2006)	**Aim**-Identify the variables that characterise the abused women with disabilities and the context within which they live. **Participants and eligibility criteria**- Women presenting to specialty clinics with physical disability that limited one or more major life activity, including mobility and self-care. Participants excluded if they have cognitive or communication impairments or mental health problems that would significantly impair their ability to respond to questionnaires. **N-**415 **Statistical analysis**-Pearson correlation and logistic regression. **Method** -survey/questionnaire. **Country**- USA **Measures**- WHO definition used for disability. Measures clearly described for measuring functioning and health status. The Abuse Assessment Screen-Disability was used to measure abuse.	-Selected individuals are likely to represent the target population. -This research recruited through clinics meaning that these women had to be accessing some sort of care, which may bias the sample. Also, individuals with cognitive or communication difficulties were excluded meaning the findings are not necessarily applicable to those individuals. Also, only females were included so this research does not represent males. -81% of the potential sample took part.

Paper	Method- participants, recruitment, N, statistical analysis	Critique
		Ethical approval: Two ethic boards granted ethical approval.
15) Oktay & Tompkins (2004).	**Aim**-Report the results of a survey relating to people who receive personal assistance who experience violence. **Participants and eligibility criteria**- People with physical disability who require personal assistance. **Recruitment**-local advocacy organisations and organisations for people with spinal cord injuries were asked to contact their members. The anonymised contact details of anyone wanting to take part in the study were passes to the researchers. **N**-84 (two thirds were men). **Statistical analysis**- statistical tests not stated. Prevalence (%) reported but also statistical significance between different prevalence's reported. **Method**- cross sectional. **Country**- not reported. **Measures**-Attendant mistreatment interview schedule.	-Selected individuals are likely to represent the target population. -It is unknown whether these participants are a representative sample of the whole population. -It is unknown what percentage of the sample population took part. - **Ethical approval**: not stated.
16) Pestka & Wendt (2014).	**Aim**-Explore significant relationship experiences for women living with intellectual disability throughout their lifespan to identify examples of women's search for belonging in the context of domestic abuse relationships. **Participants and eligibility criteria**- four women aged 20-70. Mixed of single, divorced and married. With intellectual disability. **Recruitment**-through disability services. **N-**4 **Statistical analysis**- performative dialogical analysis. **Method**- qualitative. Narrative interviewing. **Country**- Australia.	-It is unknown whether the participants are representative of the target population as no measure of disability was used. -It is unknown whether the participants are representative of the population as a whole, although they are all women so males are not represented. -Representative sample of the whole population? Unknown. -It is unknown what percentage of the sample population took part

Paper	Method- participants, recruitment, N, statistical analysis	Critique
	Measures- no measure of intellectual disability or abuse. Domestic abuse clearly defined.	-**Neutrality**- It seems the aims of the study guided the content. **Ethical approval**: South Australia Human research ethics committee.
17) Saxton, Curry, Powers, Maley, Eckels, & Gross (2001)	**Aim**- To investigate the perceptions and experiences of abuse by personal care assistants among women with physical and cognitive disabilities. **Participants and eligibility criteria**-Women with physical disabilities or physical and cognitive disability who regularly use personal assistant service, either by paid staff or family and friends. Aged 19-70. **Recruitment**-Recruited through independent living centres and disability service organisations. Disability description was broad; mobility problems, cognitive and mobility problems, health conditions, blind, and 3% declined to disclose what their disability was. **N-** 72 **Statistical analysis**- Ethnographic and content analysis technique. **Method**-qualitative. 49 participants in focus groups and 23 individual interviews. Open interview but as controlled as possible- interview questions and facilitators piloted. **Country**- USA **Measures**-No measure of disability and/or abuse.	-Selected individuals are likely to represent the target population. Some participants didn't disclose their disability although they were in receipt of personal assistance so still likely to represent target population. - This sample is representative of the female population but males are not represented. - The percentage of potential participants that took part is not stated. -**Other comments**: although the types of disability are listed, we don't know who said what in the interviews. Numerous quotes to back up themes. **Ethical approval**: Not stated.
18) Schröttle & Glammeier (2013)	**Aim**- Compare domestic abuse experiences of women with and without disabilities. **Participants and eligibility criteria**-Women with disabilities aged 16-65 years, living in Germany. Living in households and institutions. Various disabilities including physical, intellectual, visual, hearing, mental disabilities and chronic disease although no definition of disability included.	-This sample is likely to represent the target population although the types of disability that are included are so broad, it is difficult to draw out any strong conclusions about each specific group of people.

Paper	Method- participants, recruitment, N, statistical analysis	Critique
	Recruitment- National survey **N-**1,561 **Statistical analysis**-Qualitative interview. Chi squared and t-tests used for prevalence and risk factors. **Method**- qualitative. **Country**- Germany **Measures**- Abuse well defined and operationalised. Questionnaire similar to German representative survey on violence against women in general population. No information on what was different. Special consideration for adapting this for people with an intellectual disability.	- This sample is representative of the female population but males are not represented. - The percentage of potential participants that took part is not stated. -**Other comments**- very few quotes used to back up the qualitative information. **Ethical approval**: Not stated.
19) Smith (2008)	**-Aim**- Examine prevalence and risk factors for domestic abuse in women and men with disabilities. **Participants and eligibility criteria**- People with disabilities. Disability defined as "are you limited in any way in any activities because of physical, mental or emotional problems". **Recruitment**- Random survey. Further details not provided. **N**- 219,911 women with disabilities. Number of men not given. **Statistical analysis**- Chi squared and logistic regression. **Method**- cross sectional **Country**-USA **Measures**-Behaviour risk factor surveillance system- an annual random survey. The questionnaire used can be accessed online. Violence defined- only asked about physical and sexual violence.	- The definition of disability employed is so broad that some participants will represent the target population and some will not. - This sample is likely to be representative of the population as a whole although the number of male participants is not stated so it is not possible to determine how representative of the male population this research is. - The percentage of potential participants that took part is not stated. -**Other comments** Not all data provided for the analysis relating to men. **-Ethical approval**: Not stated.

Paper	Method- participants, recruitment, N, statistical analysis	Critique
20) Walter-Brice, Cox, Priest & Thompson (2012).	**Aim**-Ask women with intellectual disability about their experiences of domestic abuse within the context of intimate partner relationships. Examine whether having a label of intellectual disability influenced access to services and support. **Participants and eligibility criteria**-women, 27-50 years, who have experienced domestic abuse. **Recruitment**-Positive sampling through women's groups for women with intellectual disability. **N**-five **Statistical analysis**- qualitative. Interpretive phenomenological analysis. **Method**- interview, qualitative. **Country**- UK. **Measures**- None. Domestic abuse defined according to 'Women's Aid Federation'.	-There is no measure for disability so it is unknown whether the participants in this study represent the target population. -This is a very small sample and only includes women so is unlikely to represent the population as a whole. - The percentage of potential participants that took part is not stated. **Ethical approval**: Not stated
21) Ward, Bosek, & Trimble (2010).	**Aim**- to explore dating and romantic relationships among adults with developmental disabilities and to identify the nature and extent of interpersonal violence in their relationships. **Participants and eligibility criteria**- Men and women with intellectual disability with sufficient verbal skills to answer interview questions. People with severe intellectual disability excluded. Participants must live in a home other than with parents and with no more than three peers and live without continuous supervision. **Recruitment**- A letter was sent to service agencies, who then contacted eligible participants. **N**-47	-The participants in this study are likely to represent the target population although intellectual disability is not defined. -Very selective inclusion criteria were used meaning this sample may not be representative of the population as a whole. - 37% of the target sample took part. -**Neutrality**- The interviewers had experience in this area so may have biased the interviews. -**Other comments**- good use of quotes to back up statements.

Paper	Method- participants, recruitment, N, statistical analysis	Critique
	Statistical analysis- Qualitative analysis (partially described although the type of analysis not reported). Quantitative analysis involved chi-square analysis to look at incidence of domestic abuse in people with intellectual disability. **Method**- cross sectional, semi-structured interviews. **Country**- USA- Alaska. **Measures**- The authors produced a semi structured interview. Details are provided about the method for developing the interview but the not what questions were included. Domestic abuse recorded by participants endorsing a statement relating to abuse. No measure of disability.	**-Ethical approval**: Ethical approval granted.

Evaluating the quality of the papers

The papers included in this literature review are of mixed quality. Seven papers use a qualitative approach to perform an initial exploration of the topic area (Hague et al., 2011; Hassouneh-Phillips & McNeff, 2005; Lightfoot & Williams, 2009; Nosek et al., 2001; Pestka & Wendt, 2014; Saxton et al., 2001; Walter-Brice et al., 2012). 14 papers used a quantitative or mixed method design and had sample sizes ranging from 19 to 219,911 participants (Ballan et al., 2014; Barrett et al., 2009; Brownridge, 2006; Coker et al., 2005; Du Mont & Forte, 2014; Hague et al., 2010; Hahn et al., 2014; Hasan et al., 2014; Hickson et al., 2013; Nosek et al., 2006; Oktay & Tompkins, 2004; Schrottle & Glammerier, 2013; Smith, 2008; Ward et al., 2010). Six papers recruited participants through large scale, population wide sampling techniques, which resulted in highly representative samples (Barrett et al., 2009; Brownridge, 2006; Du Mont & Forte, 2014; Hahn et al., 2014; Schrottle & Glammerier, 2013; Smith, 2008).

This literature review aimed to identify factors that influence domestic abuse in males and females with disabilities. However, only limited conclusions can be drawn from the papers within this literature review because of several limiting features.

First, only four papers included male participants (Hahn et al., 2014; Hickson et al., 2013; Lightfoot & Williams, 2009; Oktay & Tompkins, 2004). This may be due to theories of domestic abuse, which define perpetrators as male and victims as female (Duluth Model; Pence & Paymar, 1993). However, this is a discriminatory and limiting definition of domestic abuse, which is not supported by research. Research findings show that both females and males can be victims of domestic abuse (Kimmel, 2002). Therefore, this literature review highlights the need for future research to include male participants in order to ensure that the factors influencing abuse towards males are also understood. It is not possible to ascertain from the current research whether the factors that influence domestic abuse towards men are the same or different compared to the factors that influence abuse towards women.

Second, ‘disability’ was consistently poorly defined within the research. Many of the terms used for disability are incredibly broad or ambiguous, and therefore do not provide a clear definition of the individual’s limitations when used without further clarification. For example, the terms ‘physical’, ‘emotional’, ‘mental’, ‘sensory’ and ‘developmental’ disability can all relate to a large range of disabilities with a huge spectrum of limitations. Schröttle and Glammeier (2013) referred to participants as having ‘mental disability’ or ‘mental disorder’ which could indicate an intellectual disability or mental health disorder. Other papers used ‘limitations in ability to function’ as an indicator of disability (Brownridge, 2006; Nosek et al., 2001; Nosek et al., 2006). This again is very broad and does not distinguish between people who have always experienced disability (e.g. people with developmental disorders) and people who have acquired a disability (e.g. people with spinal cord injury or mental health difficulty). The lack of consistent, clear descriptions of disability means that it is not possible to distinguish whether certain influential factors for domestic abuse are specific to certain population groups. Furthermore, a broad inclusion criteria of disabilities of different aetiologies was used in this review. This resulted in an extensive description of domestic abuse in people with disability. However, the use of such a broad inclusion criteria also resulted in a less focussed review and an inability to differentiate which factors, if any, are specific to people with certain forms of disability. Highlighting factors associated with domestic abuse in people with one form of disability may inform research focussed on domestic abuse in people with other disabilities. However, future research needs to employ standardised, operationalised definitions of disability so that distinctions can be made between which factors are uniquely associated with domestic abuse in specific population groups compared to factors that are common to people with different forms of disability.

Similarly to the lack of definition of disability, many papers also failed to adequately define domestic abuse. Some papers failed to provide any definition at all (Hasan et al., 2014; Hassouneh-Phillips & McNeff, 2005; Hickson et al., 2013; Lightfoot & Williams, 2009; Saxton et al., 2001) whereas others used modified measures to identify cases of domestic abuse without giving any details of how the measures were changed (Brownridge, 2006; Coker et al., 2005; Du Mont & Forte,

2014; Schrottle & Glammerier, 2013). There is an argument to be made for keeping the definition of domestic abuse broad, as this allows the participants to determine for themselves whether they consider their treatment abusive or not. This may reveal additional behaviours associated with domestic abuse that had not previously been considered. However, research has shown that some people are unaware that their treatment is abusive, even when this appears obvious to an outsider. For example, some people with intellectual disability may consider control and manipulation as 'normal'. Therefore, not being explicit about the definition of abuse may lead to under-reporting from certain population groups.

Finally, the majority of papers (16 out of 21) were completed in Western Countries, three papers did not report the country where the research was based and only one research study was completed in Bangladesh (Hasan et al., 2014). The cultural views and values are likely to differ between such different countries. Therefore, there is a need for more research to be conducted across different cultures to determine if there are additional differences in factors influencing domestic abuse, depending on the culture of the victim and perpetrator.

Expanding the ecological model of domestic abuse

Factors associated with domestic abuse in people with disability were categorised according to the three systems described within the ecological model; micro-system, meso-system and macro-system. These were then reviewed to determine whether they were consistent with the factors previously identified by Carlson (1997) or whether they were additional factors that hadn't previously been recorded. The prior quality assessment of the papers in this review has not been used to include or exclude any of the research findings. Given the infancy of the research topic, it is more beneficial to be overly inclusive and identify areas that warrant further investigation, than to prematurely discount factors that may help to inform our understanding of domestic abuse in people with disabilities. Instead, the findings of this literature review are presented in the context of how many papers have replicated the stated finding and the quality of those papers. This provides an indication of how

confident the reader can be in the validity of the findings being discussed. The results of this review are shown in table 4.

Micro- system factors

Similarities with the ecological model (Carlson, 1997).

Many personal characteristics were found to be associated with domestic abuse in people with disabilities, which were consistent with Carlson's original findings (1997). First, low self-esteem was highlighted in a number of studies as being associated with domestic abuse (Ballan et al., 2014, Hague et al., 2011; Hassouneh-Phillips & McNeff, 2005; Lightfoot & Williams, 2009; Schröttle & Glammeier, 2013). In some cases, this was linked to a history of abuse in the victims (Ballan et al., 2014; Lightfoot & Williams, 2009; Schröttle & Glammeier, 2013), which led to them feeling undeserving of respectful relationships and grateful of attention (Hague et al., 2011, Schröttle & Glammeier, 2013). This is a robust finding considering the number of high quality papers that replicate the result. In addition to low self-esteem, compliance (Saxton et al., 2001), a lack of self-determination (Lightfoot & Williams, 2009) and a sense of powerlessness (Walter-Brice et al., 2012) were all associated with domestic abuse in people with disabilities. These findings were only noted by one paper each so further research is needed to investigate the reliability of these claims although they appear to have face validity. Disability specific characteristics were also shown to be associated with domestic abuse. This includes an individual having limited means of escape if they have a physical disability (Hague et al., 2010) or not recognising experiences as abuse if they have an intellectual disability (Hague et al., 2011). Furthermore, some individuals with intellectual disability may lack an understanding of what is expected within an intimate relationship, making them more vulnerable to abuse (Walter-Brice et al., 2012; Ward et al., 2010).

Table 4

The micro-, meso- and macro- system factors associated with domestic abuse in people with disabilities. The table separates the factors into those which were previously reported by Carlson (1997) and factors that are additional/different to those previously reported by Carlson (1997).

	Similarities to ecological model	Differences/additions to ecological model
Micro system	**Early life experiences** Individuals with a disability are more likely to experience devaluation and rejection in childhood as well as other forms of abuse, which desensitises them to abusive relationships (Ballan et al., 2014; Lightfoot & Williams, 2009; Schröttle & Glammeier, 2013) and heightens their need for belonging (Pestka & Wendt, 2014). Throughout their lives, individuals with disability also experience increased socialisation to vulnerability and compliance, again increasing the chance of domestically abusive relationships (Saxton et al., 2001).	**Early life experiences expanded** The history of abuse in people with disabilities is likely to be different depending on the type of disability they have. For example, women with sensory and physical disabilities are more likely to be survivors of childhood physical abuse whereas women with psychiatric disabilities are likely to be survivors of childhood sexual abuse (Ballan et al., 2014). Desensitisation to intrusive medical procedures throughout life may also confuse personal boundaries and increase the risk of abuse in adulthood (Lightfoot & Williams, 2009).
	Low self-esteem Victims of abuse who have a disability are more likely to report low body and sexual esteem (Hassouneh-Phillips & McNeff, 2005; Schröttle & Glammeier, 2013). This may contribute to feeling underserving of non-abusive relationships, which has been shown to be associated with domestic abuse in people with disabilities (Hague et al., 2011).	**Low self-esteem expanded** Low self-esteem linked to unmet health needs (Barrett et al., 2009) and physical health needs (Coker et al., 2005; Hahn et al., 2014) is associated with increased risk of domestic abuse. Individuals with intellectual disability may also internalise a lack of support as somehow being their fault, further lowering their self-esteem (Walter-Brice et al., 2012).

Similarities to ecological model	Differences/additions to ecological model
Added vulnerability **Low self-determination:** Individuals with disability are more likely to have a low sense of self determination and increased powerlessness (Lightfoot & Williams, 2009; Walter-Brice et al., 2012). **Lack of knowledge:** Individuals with disabilities are also more likely to have a lack of understanding of intimate relationships (Walter-Brice et al., 2012; Ward et al., 2010), meaning they are less likely to recognise abuse (Hague et al., 2011).	**Added vulnerability** **Being trapped in an abusive relationship:** Lack of training and jobs means that it is more difficult for individuals with a disability to be independent and therefore escape an abuse relationship (Hague et al., 2010). **Personal characteristics** **Motherhood**: Mothers were more likely to be victims of domestic abuse (Ballan et al., 2014). **Marital status:** There was some evidence that victims of domestic abuse are less likely to be in a relationship (Smith, 2008) or unmarried (Barrett et al., 2009), whereas other research stated that those most at risk of domestic abuse were married (Ballan et al., 2014). **Age:** Some research suggested that domestic abuse is associated with the victim being younger (Barrett et al., 2009; Brownridge, 2006; Nosek et al., 2006) whereas Hasan et al. (2014) reported that the risk of abuse is higher in people aged 32 years and over and Oktay and Tompkins (2004) found no association between age and risk of domestic abuse. **Income**: Low income is associated with increased risk of domestic abuse (Barrett et al., 2009; Oktay & Tompkins, 2004) as is having no access to public funds (Hague et al., 2011). Individuals who are victims of domestic abuse are also less likely to have health care coverage (Barrett et al., 2009). **Activity limitations**: activity limitations are associated with prevalence (Nosek et al., 2006) and severity of abuse (Du Mont &

	Similarities to ecological model	Differences/additions to ecological model
		Forte, 2014) and ability to escape the perpetrator (Hague et al., 2010). **Education:** Higher levels of education were shown to be associated with increased risk of abuse although the authors suggested that this might be a statistical artefact (Nosek et al., 2006). Other research found that lower levels of education was associated with increased risk of abuse (Smith, 2008).
Meso system	**Social isolation** Individuals who are socially isolated are at greater risk of domestic abuse (Ballan et al., 2014; Lightfoot & Williams, 2009; Nosek et al., 2006; Smith, 2008; Walter-Brice et al., 2012). Isolation is increased through lack of employment (Ballan et al., 2014; Smith, 2008) and isolation from other carers (Hague et al., 2011). Also Hassouneh-Phillips and McNeff (2005) noted that people with physical disabilities may have limited options for forming and maintaining relationships, meaning they are more isolated and also more complacent about what they accept in a relationship. **Power imbalance** An imbalance in power between partners increases the risk of abuse (Hague et al., 2010). This power imbalance is exacerbated by an increase in dependency due to unmet health needs (Barrett et al., 2009; Schröttle & Glammeier, 2013). Furthermore, people with disabilities have a preference for being partnered with non-disabled men, which increases the	**Power imbalance** People with disabilities are not trained as employers, meaning they are deskilled in the role of employer with their care workers (Saxton et al., 2001). **Relationship characteristics** As the length of the relationship increased, the risk of abuse decreased (Brownridge, 2006). **Education disparity:** An education disparity between the partners (in either direction) increases the risk of abuse (Brownridge, 2006). **Nature of the abusive relationship:** There is a lot of evidence that abuse towards people with disabilities is more likely to be perpetrated by paid care staff or helpers (Hague et al., 2010; Hague et al., 2011; Schröttle & Glammeier, 2013) compared to family members (Oktay & Tompkins, 2004). The risk increases with those who give extensive hours of care (Oktay & Tompkins, 2004) or when there is increased dependency or carer burden (Schröttle & Glammeier, 2013). There is often personal boundary confusion between a victim and caregiver, which could constitute abuse (Saxton et al., 2001) and frustration in the carer role may lead to

	Similarities to ecological model	Differences/additions to ecological model
	power imbalance (Hassouneh-Phillips & McNeff, 2005; Saxton et al., 2001; Smith, 2008).	rough handling, which could also be experienced as abuse (Nosek et al., 2001). Abuse towards people with disabilities is rarely perpetrated by an intimate partner (Schröttle & Glammeier, 2013) and, within a residential care setting, is often perpetrated by other residents (Schröttle & Glammeier, 2013). **Dynamic between paid care staff and victim:** The difficult dynamic between paid care staff and people with disabilities makes abuse more likely. One paper reports the barrier to disciplining a staff member if you then have to ask them to assist with personal care (Hague et al., 2010), or if staff members are friends or family, this may make it more difficult to ask them to do things for you (Saxton et al., 2001).
Macro system	**Social status of people with disabilities** There is a pervasive societal devaluation of women with sensory, physical and/or cognitive disabilities, potentially perpetuating the perspective that these individuals are more deserving of violence (Hassouneh-Phillips & McNeff, 2005; Saxton et al., 2001). In Bangladesh, generous amounts of dowry are expected for marrying a woman with disabilities, highlighting the low social status of these women (Hasan et al., 2014). In these situations, if a woman experiences domestic abuse, they are often encouraged to return to their husbands (Hasan et al., 2014). **Cultural constructs of disability** People with disabilities are often viewed as unattractive (Schröttle & Glammeier, 2013), and not seen as sexual	**Barriers to seeking/receiving help** **Fear:** Individuals with disabilities may fear being institutionalised, having their funding removed, or being left without an assistant if they report abuse (Hague et al., 2010; Hague et al., 2011; Saxton et al., 2001). People with disabilities (sensory and physical) may fear not being believed if they report abuse (Hague et al., 2010) and may think that the abusers are seen as beyond reproach (Hague et al., 2010). Also, having limited means of escape may make individuals with intellectual disability less likely to report abuse (Ward et al., 2010). **Service inadequacies:** There is a lack of awareness in society and among professionals working with people with intellectual disability about the risk of domestic abuse in these individuals (Hickson et al., 2013). Domestic abuse towards people with disabilities is often not recognised by agencies as abuse (Hague et

	Similarities to ecological model	Differences/additions to ecological model
	(Lightfoot & Williams, 2009). They are also often seen as eternally children (Schröttle & Glammeier, 2013). These disempowering and discriminatory cultural constructs increase the risk of these individuals being the victim of domestic abuse (Pestka & Wendt, 2014; Schröttle & Glammeier, 2013).	al., 2011; Saxton et al., 2001) or, if it is recognised, then services are unavailable (Lightfoot & Williams, 2009) or unequipped to support the victims of domestic abuse who also have disabilities (Hague et al., 2011). Individuals with disabilities may also not trust the system so choose not to disclose abuse (Lightfoot & Williams, 2009), or, within the deaf community, family members may be used as interpreters, preventing the victim from being able to disclose their experiences of abuse (Lightfoot & Williams, 2009)
		Cultural belonging Individuals with disabilities who have experienced discrimination, have a weak sense of belonging to the local community and a low trust in family members and strangers are more likely to be the victims of domestic abuse (Du Mont & Forte, 2014). Individuals whose first language is not English in an English speaking country are also more likely to be victims of abuse (Hague et al., 2011).

Additions to the ecological model (Carlson, 1997).

In addition to the personal characteristics identified within the Carlson (1997) paper, this current review of the literature identified a number of additional risk factors for people with disabilities experiencing abuse. The majority of these risk factors are also found in the general population including having a low income (Barrett et al., 2009; Capaldi, Knoble, Shortt, & Kim, 2012; Oktay & Tompkins, 2004) lower levels of education (Capaldi et al., 2012; Smith, 2008), being unemployed (Ballan et al., 2014; Capaldi et al., 2012; Smith, 2008) being younger (Barrett et al., 2009; Brownridge, 2006; Capaldi et al., 2012;) and having unmet health needs (Barrett et al., 2009; Centers for Disease Control and Prevention, 2008; Coker et al., 2005). Social isolation has also been shown to be associated with increased risk of domestic abuse in people with and without disabilities (Hague et al., 2011; Jewkes, 2002). On the other hand, being a mother (Ballan et al., 2014) has not been reported in the general population and may therefore be specific to people with disabilities. Also, several studies included in this review reported increased risk of domestic abuse in people with disabilities who were married (Ballan et al., 2014; Barrett et al., 2009), whereas a review of the literature in the general population suggests that living arrangements (i.e. if a couple live together) is more important than marital status for predicting domestic abuse (Cattaneo & Goodman, 2005).

The papers within this literature review found additional factors that impact on a person's self-esteem, which may then increase their vulnerability to experiencing domestic abuse. First, one paper found that many individuals who experience domestic abuse had a history of childhood rejection (Pestka & Wendt, 2014). Second, victims of abuse were said to internalise a lack of support as their fault (Walter-Brice et al., 2012), meaning they may be less likely to pursue support and feel more deserving of the abuse. Third, one paper reported individual's having a perceived need to be partnered (Hassouneh-Phillips & McNeff, 2005). This may increase vulnerability to abuse as individuals may be less selective in their choice of partner.

The nature of an individual's disability is an important factor that contributes to the risk and nature of domestic abuse in its own right. For example, an individual

with sensory difficulties may not be able to see or hear their abuser approaching so has limited ability to protect themselves (Hague et al., 2010). Also, the pattern of abusive behaviour may be specifically targeted to the person's disability such as limiting access to mobility aids, belittling based on disability characteristics, or leaving people in vulnerable positions such as sitting naked on the toilet (Hague et al., 2010; Hague et al., 2011; Lightfoot & Williams, 2009; Nosek et al., 2001; Saxton et al., 2001). Also, people who require carers may not have their choices respected (Nosek et al., 2001) or experience breaches of confidentiality or invasions of privacy as a form of abuse (Hague et al., 2010; Saxton et al., 2001). Although each of the specific forms of abusive behaviours may only be noted in one paper each, taken together these findings consistently suggest that the nature of domestic abuse may vary depending on the individual's specific disability.

Meso-system factors

Similarities with the ecological model (1997).

The current review supports the findings reported by Carlson (1997) that social isolation is an important characteristic in the immediate social environment of victims of domestic abuse with disabilities (Ballan et al., 2014; Barrett et al., 2009; Lightfoot & Williams, 2009; Nosek et al., 2006; Smith, 2008; Walter-Brice et al., 2012). This review also found further evidence to support the assertion that a power imbalance between the victim and perpetrator is an important factor in abuse (Barrett et al., 2009; Hague et al., 2010; Saxton et al., 2001; Smith, 2008). Also, the papers within this review verified the finding that a victim of abuse who has disabilities has limited escape options available within their immediate social context (Hague et al., 2010, Ward et al., 2010) and they may refrain from reporting abuse for the fear of being institutionalised if no one else is available to provide the care they require (Hague et al., 2010).

Additions to the ecological model (1997).

This review built upon the findings reported by Carlson (1997). First, in terms of social isolation, one paper identified the fact that abusers may isolate their victims

with disabilities from their other carers, further increasing their vulnerability and reducing their means of escape (Hague et al., 2011). Escape options are also limited within the deaf community as family members are often used as interpreters (Lightfoot & Williams, 2009). If they are the abuser, this would be a significant barrier to the victim accessing help from others. Also, it was noted that people with disabilities are unlikely to report their abuse (Barrett et al., 2009) and it often goes unnoticed by other people (Hague et al., 2010), meaning that victims are less likely to get support to leave an abusive relationship.

This review also added to the findings relating to the importance of power imbalance in abusive relationships (Carlson, 1997). For instance, Brownridge, (2006) found that a disparity in education level between the victim and perpetrator, in either direction, was associated with domestic abuse. A third of papers included in this review reported that care workers, paid or unpaid, were likely to be the perpetrator of abuse towards people with disabilities (Hague et al., 2010; Hague et al., 2011; Nosek et al., 2001; Oktay & Tompkins, 2004; Saxton et al., 2001; Schröttle & Glammeier, 2013; Smith, 2008), especially when there is increased burden and dependency on the carer (Schröttle & Glammeier, 2013) or when there is frustration in the caring role (Nosek et al., 2001). Care is often provided by family members or friends. This, combined with the fact that people with disability are not trained to be employers, may increase the difficulty in establishing and maintaining professional relationships with clear boundaries (Lightfoot & Williams, 2009; Saxton et al., 2001). The nature of care work complicates this further, for instance, it would be difficult to discipline someone (i.e. in an employer role) and then require them to assist you with personal care (Hague et al., 2010).

An individuals' immediate social environment may further influence the development of abusive relationships. Those who live in a residential care setting were shown to be at risk of abuse by other residents (Schröttle & Glammeier, 2013). Also, individuals with a disability may have limited options for forming other relationships, which may influence their decision making in terms of entering into or staying in an abusive relationship (Hassouneh-Phillips & McNeff, 2005).

The meso-level characteristics discussed in this section do not necessarily add any entirely new factors to the ecological model of domestic abuse. However, these papers add weight to the conclusions drawn in Carlson's original paper (1997) by giving specific examples relating to each factor. The findings that isolation and a power imbalance are key characteristics of an abusive relationship are reinforced by the large number of studies that replicate these findings.

Macro-system factors

Similarities with the ecological model (1997).

As noted by Carlson's review (1997), there are several cultural factors which increase the risk of an individual with disability being the victim of domestic abuse. These include the low social status associated with disability (Hasan et al., 2014; Hassouneh-Phillips & McNeff, 2005; Pestka & Wendt, 2014; Saxton et al., 2001; Schröttle & Glammeier, 2013), which may dehumanise individuals and lead the perpetrator to feel more 'justified' in their actions, or further reinforce the sense of disempowerment felt by an individual with disabilities (Schröttle & Glammeier, 2013). Also, people with disabilities are not seen to be sexual or in need of relationships (Lightfoot & Williams, 2009), which may act as a barrier to services recognising people with disability as potential victims of domestic abuse (Lightfoot & Williams, 2009).

Additions to the ecological model (1997).

A search of the literature also revealed additional macro-level factors associated with abuse in people with disability that were not noted in Carlson's ecological model (1997). One main area identified was a lack of responsiveness of services in supporting victims of abuse with disability to access help (Hague et al., 2011). Abuse perpetrated by a care worker is often not acknowledged by agencies as this falls outside of the accepted definition of domestic abuse (Hague et al., 2011; Saxton et al., 2001). One paper reported that victims were not believed about abuse and victims felt as though the abuser was seen as "saintly and beyond reproach" (Hague et al., 2010). Other papers reported that, although training in the area of abuse

in people with disability was viewed as important (Hickson et al., 2013), there continues to be a lack of knowledge and awareness by professionals in relation to this topic (Hickson et al., 2013; Walter-Brice et al., 2012).

Cultural factors exacerbate dependency and isolation in people with disability. For example, undervaluing people with disability means that there is a lack of training and jobs made available for these individuals (Hague et al., 2010). Individuals with disability often face discrimination (Du Mont & Forte, 2014), have low trust in family members and strangers (Du Mont & Forte, 2014) and have a weak sense of belonging in their local community (Du Mont & Forte, 2014), which all contribute towards increased isolation for these individuals.

Furthermore, specific cultures may increase the risk of domestic abuse continuing. For example, black people are less likely to 'trust the system' (Lightfoot & Williams, 2009), meaning they are less likely to seek help from services. Also, some cultures encourage women to return to their husbands even if they have been abused, regardless of disability (Hasan et al., 2014). The deaf community was described as a small world, where the victim would feel pressured to not disclose abuse (Lightfoot & Williams, 2009).

Evaluating the use of the ecological model

The ecological model provides a helpful framework for describing the factors that contribute towards abuse in people with disability. There are numerous factors associated with abuse at each of the micro, meso and macro levels of the model. Splitting the factors associated with abuse in this way makes it easier to coherently describe abuse and to identify gaps in research knowledge. However, using a model such as this may superficially simplify the notion of abuse as the identified factors do not necessarily fit into such distinct categories. For example, feeling underserving of a relationship may be viewed as a personal characteristic (micro-level), but this will then influence the dynamics within an intimate partner relationship (meso-level). Similarly, an individual's preference for a non-disabled partner (micro-level) would

potentially increase the power dynamics between the victim and perpetrator (meso-level). Therefore, by separating out these factors, as indicated by the ecological model, the richness of the description of domestic abuse may be undermined and the complexity of this occurrence may be inadequately represented. It may therefore be helpful to develop the ecological model further to connect the individual factors in a way that depicts the interactions and influences between the different factors.

Defining domestic abuse

One of the critiques of many of the papers included in this literature review was the lack of operationalised or standardised definitions of abuse, or, that if a definition was employed, this was not consistent across the different papers. This is problematic for several reasons. First, it is not possible to accurately compare research findings from papers that employ different definitions of abuse. Second, it is not possible to ascertain true prevalence estimates of abuse if there is disagreement about what this abuse entails. This would also make it more challenging to inform domestic abuse services about the extent of the problem. Third, failing to provide a definition of abuse that adequately encompasses all types of abusive behaviours may lead domestic abuse services to claim that the abuse experienced by individuals with disability falls outside of their remit. Finally, failing to encompass disability specific abuse in the definition of domestic abuse may limit the individual with disability's understanding of abuse and how this applies to them, possibly discouraging them from seeking help.

A robust finding of this review is that the perpetrator of abuse towards people with disability is often their carer, or other residents in a care setting. Sometimes the carer is also an intimate partner or family member (Hague et al., 2010) but in other instances care is provided by agency staff (Hague et al., 2010, Hague et al., 2011; Schröttle & Glammeier, 2012). Another strong finding was that the abuse these individuals experience is often specifically targeted at their disability. These acts include behaviours that would not typically be considered abusive unless the individual's disability is taken into account, for example, removing the battery of a wheelchair or leaving someone sat on a toilet.

The home office definition of domestic abuse is;

> "any incident or pattern of incidents of controlling, coercive, threatening behaviour, violence or abuse between those aged 16 or over who are, or have been, intimate partners or family members regardless of gender or sexuality. The abuse can encompass, but is not limited to:
>
> - psychological
> - physical
> - sexual
> - financial
> - emotional"

This definition is broad and would encompass the disability specific abusive acts discussed previously. However, this definition does not apply to abuse perpetrated by a carer or other resident, even though this occurs in a domestic environment and is consistent with the other features of the definition of domestic abuse. Therefore, the findings of this review indicate that an amendment to the current definition of abuse should be considered to include abusive acts committed by individuals other than family members or intimate partners. Ballan et al., (2014) uses a definition of abuse taken from the New York State Coalition Against Domestic Violence (2011). This definition states that domestic abuse entails;

> "physical, sexual, psychological, disability-related, and economic abuse, and is perpetrated by one person against their intimate partner. Domestic violence can also be perpetrated by and/or against a member of the same family or household" (para. 1).

Using a definition such as this would mean that abuse committed by carers or residents in a care home could also be considered acts of domestic abuse. This could allow the victim to access domestic abuse services more easily and have their experience appropriately recognised.

Clinical implications

This review highlights a number of important clinical implications. First, it is important for domestic abuse services to adapt in order to be accessible for people with a range of disabilities. Second, it is important for people with disabilities to receive regular contact with services away from their carers. This is vital to give them the opportunity to disclose abuse if it is being perpetrated by carers. Third, it is important that clinicians have a thorough understanding of what may be considered abuse in relation to the people that they are supporting. Then, during times of contact with these individuals, it is important for clinicians to explicitly ask about any possible abuse and to be mindful that the individual with whom they are speaking may not have a full understanding of what abuse refers to. Therefore, the individual may need support and information around this topic in order to disclose if abuse is occurring.

Conclusion

The act of domestic abuse towards people with disabilities is influenced by a huge number of factors including individual characteristics, complex dynamics between the victim and the abuser and cultural beliefs and values, which underlie and exacerbate these personal and relational factors. The myriad of factors can be helpfully categorised according to the ecological model (Carlson, 1997), although it is important to recognise that the factors influencing and maintaining domestic abuse at the micro, meso and macro-levels interact with one another rather than occurring in isolation.

The literature focussing on domestic abuse in people with disability is becoming increasingly established. However, the quality of future research needs to be improved by more clearly defining both the nature of disability experienced by the participants and the nature of domestic abuse which they are referring to. Future research is also needed to address the dearth of information relating to male abuse victims.

The findings reported in this review also suggest that an amendment to the generally accepted definition for domestic abuse is needed. The current definition and therefore understanding of domestic abuse does not adequately capture the experience of people with disabilities in terms of the range of possible perpetrators of abuse including paid and unpaid care staff and fellow residents in a care setting. Understanding the nature of these relationships is vital for guiding psychological interventions and increasing the likelihood that victims of abuse are identified and given the support they need. Better identification of domestic abuse would also enable more accurate prevalence estimates to be determined, which could inform the development of services which currently fail to meet the needs of abuse victims with disabilities (Tomasulo, Keller & Pfadt, 1995).

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Increasing staff confidence and implementation of trauma therapy skills; a service improvement project

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Abstract

This service improvement project followed the Model for Improvement framework (Langley et al., 2009), comprising two 'plan-do-study-act' cycles. The aim of this project was to support NHS staff without specialist psychological therapy skills to provide phase one trauma work to service users with complex post-traumatic stress disorder (C-PTSD). Semi-structured focus groups were used to elicit staff views on what would be helpful to facilitate this work (n= 8). The findings from these focus groups informed the production of a resource pack that staff could use to assist phase one of trauma focussed work, which included psycho-education, stabilisation and emotion regulation training. Questionnaires were used to assess the amount of phase one trauma based work completed and the perceived level of confidence in staff before and after the introduction of the resources. A total of 16 participants provided ratings before the introduction of the resources and nine participants provided ratings following the introduction of the resources. Findings indicated that the use of phase one trauma skills by staff without psychological training had either stayed the same or increased following the introduction of the resources and staff confidence ratings were higher when staff had access to the resources compared to before the resources had been made available. These findings demonstrate that recovery from C-PTSD can potentially be facilitated by developing resources for staff to use with service users.

Introduction

Post-Traumatic Stress Disorder (PTSD) is a highly prevalent and debilitating condition (Kearns, Ressler, Zatzick & Rothbaum, 2012) characterised by a number of symptoms including intrusions (flashbacks, nightmares etc.), avoidance of trauma stimuli or PTSD symptoms, changes in mood, and changes in activity and/or arousal (DSM-V; American Psychiatric Association, 2013). To diagnose PTSD, the individual must have experienced a 'stressor', where there was the threat or occurrence of death and/or sexual or physical violence. There is growing evidence that survivors of prolonged and repeated stressors such as neglect and abuse in childhood or torture in adulthood may go on to develop a more complex myriad of symptoms, conceptualised as complex post-traumatic stress disorder (C-PTSD; Resick, Bovin, Calloway, Dick, King, Mitchell et al., 2012). As many as 75-98% of individuals with severe mental illness have experienced multiple traumas, which may make them vulnerable to C-PTSD (Grubaugh, Zinzow, Paul, Egede, & Frueh, 2011). Individuals with C-PTSD will experience the symptoms of PTSD (DSM-V; American Psychiatric Association, 2013) in addition to other difficulties including alterations in regulation of affect, attention or consciousness (e.g. dissociative experiences), self-perception, relations with others and systems of meaning such feelings of despair and hopelessness (Luxenberg, Spinazzola, & Van der Kolk, 2001).

The general consensus for working with C-PTSD is a phase based approach comprises three phases; stabilisation, detailed reliving and reprocessing of the trauma memory (exposure), and reclaiming one's life (Cloitre, Courtois, Charuvastra, Carapezza, Stolbach, & Green, 2011; Cloitre, Koenen, Cohen & Han, 2002; Herman, 1992). Phase one of treatment includes techniques such as grounding, psycho-education and emotion regulation training and is considered complete when the service user feels ready to move on (Herman, 1992). A consensus of experts in this area indicate weekly session as most appropriate for phase one of therapy and endorse a time scale of three months as the likely length of time required for an improvement to be observed (Cloitre et al., 2011). In a randomised control trial, a phase based approach starting with eight weeks of training in affect and interpersonal regulation, followed by exposure, was shown to be associated with better clinical outcomes

compared to supportive counselling followed by exposure or skills training followed by counselling (Cloitre, Stovall-McClough, Nooner, Zorbas, Cherry, Jackson et al., 2010). In this study, skills training in affect and interpersonal regulation followed by exposure resulted in higher rates of PTSD remission, greater improvements in interpersonal problems and lower rates of PTSD symptoms between exposure sessions (Cloitre et al., 2010).

The following project was conducted within the Avon and Wiltshire Mental Health Partnership National Health Service (NHS) Trust (AWP). The NHS is a national health service paid for by British tax payers, which is free at the point of entry. The NHS provides primary, secondary and tertiary physical and mental health services. AWP is a significant mental health services provider across the southwest of England, including Bath, North East Summerset, Bristol, North Summerset, South Gloucestershire, Swindon and Wiltshire (AWP, 2016). AWP employs over 3300 full time equivalent staff, including mental health practitioners, social workers and nurses (Turton, 2016) across over 100 different inpatient, community and specialist mental health teams (AWP, 2016). Prior to this project, all phases of trauma treatment were predominantly carried out by specialist psychological therapists within AWP. This was arguably a costly and inefficient use of resources as other professionals, who had more contact time with service users, may have been better placed to carry out phases one and three of treatment. Nationally, there is a pressure to make savings and one way to achieve this is for cheaper staff to deliver the same interventions. Therefore, the service identified this as an area in need of improvement and aimed to increase the delivery of phases one and three of trauma treatment by non-specialist psychological therapists within the Trust. This project relates to the provision of phase one of treatment only.

The Bennett-Levy model of learning describes the acquisition of therapist competence in delivering a therapeutic approach (Bennett-Levy, 2006). Applying this model, for staff to effectively provide phase one of trauma treatment, they would need to gain declarative, procedural and reflective knowledge of the topic area (Bennett-Levy, 2006). Therefore, staff would need to understand the treatment rationale and

protocols (declarative knowledge), transfer these skills into practice with specific service users (procedural knowledge) and finally, reflect on the use of these techniques in supervision to refine their skills and techniques (reflective knowledge). AWP already provided an educational session for staff members to improve their knowledge and confidence of assessment and treatment of PTSD and C-PTSD. Staff were also already encouraged to seek supervision regarding the trauma based work they completed. This addressed the declarative and reflective learning components of the Bennett-Levy model. However, the service identified a lack of staff confidence in applying these skills, which limited the use of these skills in day to day practice. This was indicative of a lack of development of procedural skills. Therefore, the overall aim of this project was to facilitate community team staff, who do not have specialist psychological therapy training, to undertake preparatory trauma work (i.e. phase one) within a phase based model, which would increase procedural learning opportunities.

This project adhered to the Model for Improvement (Langley, Nolan, Nolan, Norman, & Provost, 2009), which has generally been adopted within the NHS and provides a framework for service development. According to this model, before commencing a service development project, three questions must be answered: what are we trying to accomplish, how will we know that a change is an improvement, and what change can we make that will result in improvement. Answering these questions yielded the following objectives for this service improvement project:

1. Determine what resources would be useful to facilitate the use of phase one trauma techniques with service users and improve staff confidence when doing this work.
2. Develop resources to support staff with no psychological therapy training to carry out phase one work.
3. Evaluate whether staff use phase one trauma techniques more with service users following the introduction of the resources.
4. Evaluate the change in staff members' perceived confidence in using phase one trauma techniques with service users following the introduction of resources.
5. Describe how useful staff perceived the resources to be in facilitating their phase one trauma based work.

Method overview

This project followed a longitudinal, mixed-methods design. Ethical approval for this project was granted by the University of Bath Ethics Committee and AWP Research and Development team (see appendix C). This project adhered to the Model for Improvement (Langley, Nolan, Nolan, Norman, & Provost, 2009), which has been adopted by the NHS. This model comprises four stages: plan, do, study, act. The following project involved two separate plan-do-study-act cycles. For clarity, these two cycles will be discussed separately.

Phase one: Plan

Two focus groups were organised with the aim of gathering staff views from AWP regarding what resources would facilitate trauma focussed work within their service.

Phase one: Do

Focus group one included two clinicians working in AWP, who specialise in trauma based work. These participants were recruited by directly contacting them by email and in person and inviting them to take part in the project. Focus group two included an opportunity sample of six practitioners working within AWP who had regular contact with service users with a history of trauma. A two-phase approach was used to recruit these individuals; firstly emailing potential focus group attendees and then speaking with them in person to provide a rationale and time and location for these groups. It was made clear to all potential focus group attendees that they were under no obligation to join the focus groups.

Participants who attended the focus groups were asked for input regarding the contents and design of the resources. A semi structured interview schedule was used during these focus groups (see appendix D1 and D2 for the interview schedules).

The focus groups were audio taped, transcribed verbatim and then analysed using thematic analysis (Braun & Clarke, 2006). Thematic analysis was selected as this provides a rich description of the data and is ideal for pulling out implicit and explicit ideas from the participants' responses (Braun & Clarke, 2006). A second rater, a Clinical Psychologist in Training, also analysed the material independently to ensure reliability of the main themes. Consensus for the themes was reached through discussion between the two independent raters. The two raters had 100% agreement on the themes they identified.

Phase one: Study

The main themes were identified and depicted in a thematic map (figure 1). Theme one related to the perceived skill set and resources already available to the team. This provided a point of reference for the staff to describe what they felt would be useful when considering the development of additional resources. For example, participant six stated "In terms of the sort of safety and stabilisation type work, I've tended to use emotional regulation type worksheets and things that I've got from the internet." Participant five later went on to say;

> "but we don't really have a central place or structure for any sort of work sheets or any guidance on how to use the work sheets or when they would be appropriate, or for what reason you'd be using them for".

Theme two centred on the perceived barriers that prevented or limited trauma based work. This included a lack of confidence and being fearful of exacerbating the service user's distress. Participant three commented; "If I'm not confident, I'm not going to start digging my fingers into something I'm going to make worse. So, I'm going to sort of hold back really". Similarly, participant one stated; "I think trauma itself is quite evocative for people. They can be quite fearful regarding making people worse and not wanting to necessarily start a client talking about something that they can't contain…".

Participants shared their thoughts about what sort of trauma resource would be helpful (theme three). Participants consistently requested a centralised resource pack, containing "psycho-education type resources to support understanding" (Participant four), "that you can work through" (Participant six) and where the service user can take something away and practice independently. Participants also highlighted the importance of a "framework for staff" to know what to do and when, such as "Maslow's hierarchy of needs" (participant one).

The fourth and final theme related to the perceived benefits of having a centralised resource pack. This included empowering staff to "have a focus and to feel a little bit confident that [they] know what [they] are doing" (Participant three). In addition to this, benefits were noted for the service user including an increase in staff members' ability to normalise a trauma response and the service user receiving consistent care across the service.

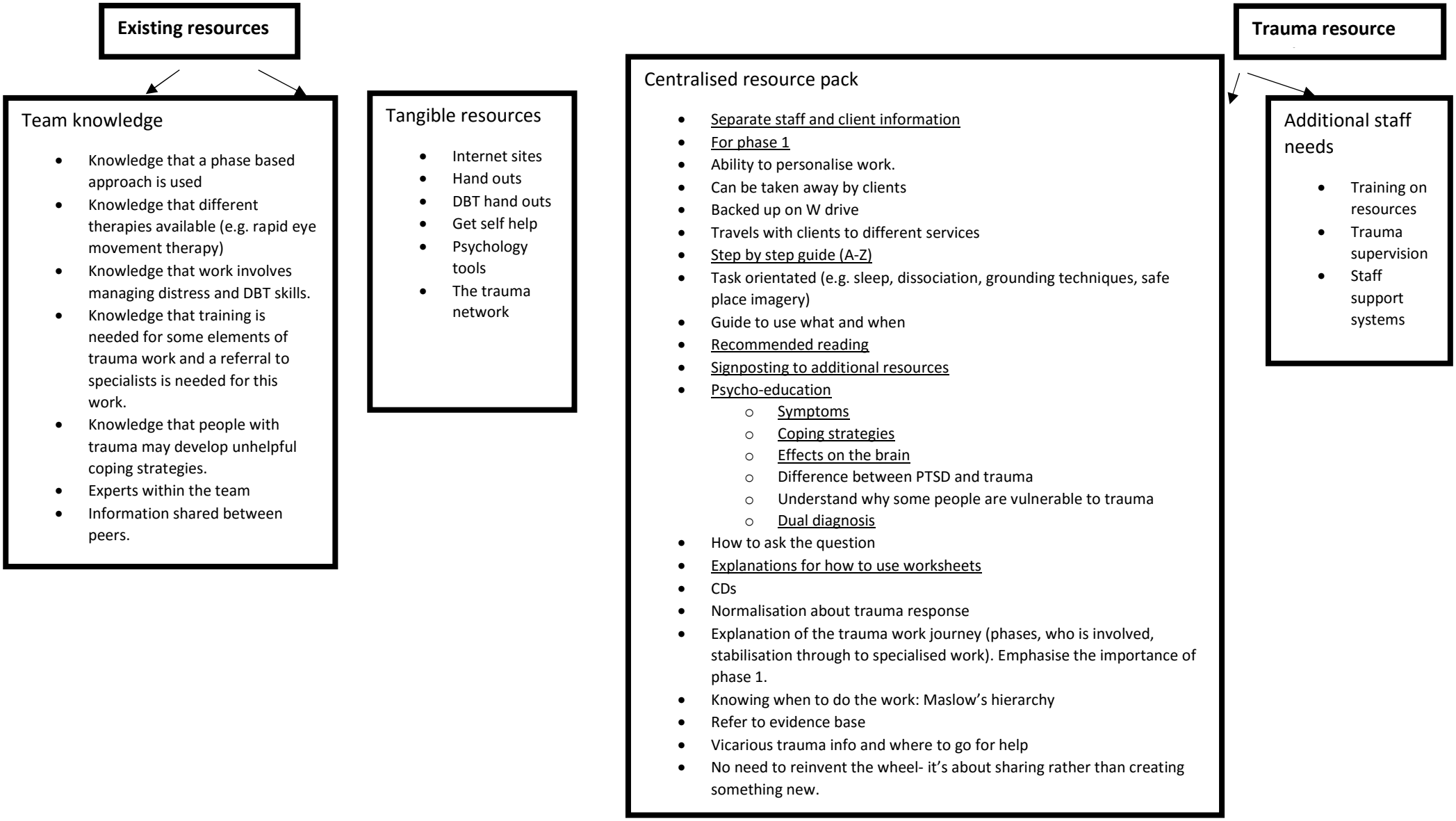

Figure 1. Thematic map. Themes resulting from thematic analysis of the focus group data. Underlined font denotes information that was supported by both focus groups.

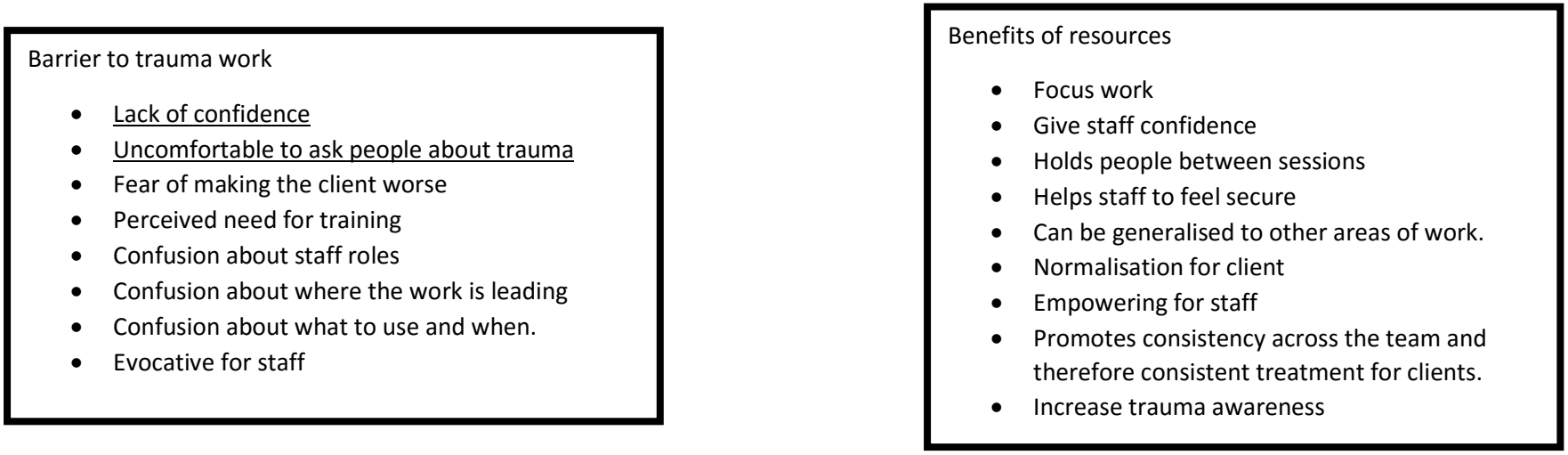

Figure 1. Thematic map. Themes resulting from thematic analysis of the focus group data. Underlined font denotes information that was supported by both focus groups.

Phase one: Act

The results from the focus groups (study phase) were used to inform the decision to develop a centralised resource pack. This was mainly a consolidation of existing worksheets and information sheets that are freely available online, combined with a selection of information sheets developed specifically for this purpose. The resource pack was made available in two formats; one ring binder folder and one electronic version stored on AWP's shared network space. Both versions were formatted so that information could be added to produce a resource that can grow and evolve over time. (See appendix E1-4 for the contents of the resource pack and a selection of the resources).

Phase two: Plan

In phase one, resources were developed to be used by staff when completing trauma based work. The purpose of these resources was to support staff to apply their declarative knowledge of trauma work into a practical phase of learning. The aim of phase two is to evaluate the impact of having access to the trauma resources developed during phase one. Changes in staff confidence when doing trauma focussed work will be assessed. The perceived usefulness of the resources will also be evaluated.

Phase two: Do

Staff confidence in implementing trauma based techniques was measured at two baseline points and one follow up point in an attempt to track changes in staff confidence over time. Baseline one coincided with the focus groups and baseline two occurred four months later when the resources were introduced. The follow-up data collection point occurred after another four months. A self-report questionnaire, specifically designed for this project, was administered at each of the three time points. This questionnaire measured staff's perceived confidence in identifying service users who may benefit from trauma focussed work, providing psycho-education about trauma and ability to use trauma techniques with service users (appendix F). At follow up, a second questionnaire was used which also asked participants to compare their

current confidence to their estimated confidence if the resources had not been made available (appendix G).

Eight participants took part in the first baseline, 11 participants took part in the second baseline and nine participants took part in the follow up. At the two baseline points, potential participants were approached by a researcher via email and/or in person and invited to take part. They were informed of a time and location to meet the researcher to collect the questionnaires. At follow up, the individuals who had participated at each of the baseline points were approached in person by a researcher and invited to complete the follow up questionnaire. It was not recorded who was approached to take part in this study, therefore it is not possible to ascertain a response rate of participation. Figure 2 shows the pattern of attrition and retention of participants throughout these time points.

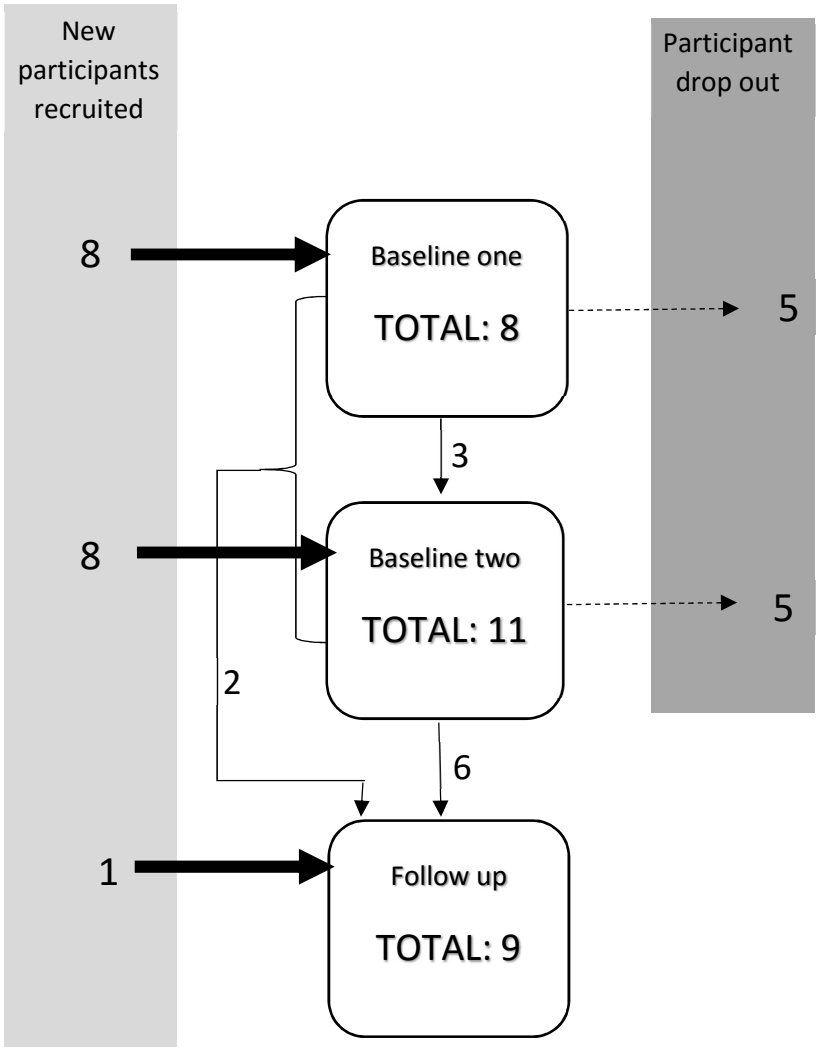

Figure 2. Pattern of participation. This figure illustrates the retention of participants and the incorporation of new participants across the three points of data collection.

Phase two: Study

An initial investigation of the data was conducted to assess the difference in staff confidence between the baseline and follow up time points. This indicated that the proportion of participants rating themselves as low in confidence ("not at all confident" and "a little confident") was higher in the baseline conditions compared to the follow up time point when the resources were available. This was the case for confidence in identifying service users who may benefit from trauma work, confidence in providing psycho-education about trauma and confidence in using trauma techniques. It was not possible to use formal statistical methodology to analyse the

change in confidence over time as the sample size was too small and there was a lack of consistent participants across the different time points.

Due to the methodological limitations of this study (low retention of participants across different time points), it was not possible to assess change in staff confidence over time. As an alternative, Statistical Package for the Social Sciences (IBM SPSS Statistics, 22) was used to conduct a Wilcoxon signed-rank test to compare current staff confidence in various areas of trauma work to their predicted levels of confidence if the resources had not been made available in the nine participants from the follow up condition (i.e. predicted change in confidence rather than actual change in confidence). Extra caution is warranted when interpreting these findings as these results cannot be considered a direct measure of change in confidence and may also be susceptible to demand characteristics. For instance, individuals who invested a large amount of time and effort throughout the service improvement project may have been more motivated to identify a positive result rather than a neutral or negative result. Furthermore, participants may have predicted that the researchers hypothesised higher confidence ratings after the introduction of resources compared to before and therefore answered according to what they felt was the desirable response. It was predicted that staff would feel more confident with access to resources compared to without, meaning one-tailed p-values are reported. Confidence ratings were made using the five point Likert scale where "not at all confident" equalled zero and "extremely confident" equalled five. There was a positive trend between current staff confidence to identify service users who would benefit from trauma based work (Med= 3.0, Range= 2.0-3.0), compared to predicted level of confidence if the resources had not been made available (Med=2.0, Range=1.0-3.0; $Z = -1.86$, $p = 0.06$). There were significant differences between current staff confidence to provide psycho-education around trauma (Med=, Range= 1-4), compared to predicted level of confidence if the resources had not been made available (Med= 1.0 Range=0.0-3.0; $Z = -2.64$, $p < 0.01$) and current staff confidence in using trauma skills and techniques (Med= 3.0, Range= 1.0-3.0), compared to their predicted level of confidence to use the same skills if the resources had not been made available (Med=2.0, Range= 0.0-3.0; $Z = -2.12$, $p < 0.05$).

Staff were also asked to rate how useful they found the resources. Of the participants who stated that they'd had an opportunity to use the resources (n=6), on average, they had used the resources 'about half the time' that they had completed trauma based work. Table 1 shows which resources had been used by staff who had the opportunity to do so, and how useful they had found them. Usefulness was measured on a five point Likert scale (0=not at all useful, 1=slightly useful, 2= somewhat useful, 3=very useful, 4= extremely useful).

Table 1

Percentage of staff who used each resource, out of the staff who had the opportunity to do so.

Resource	**Percentage of staff who have used the resource (n)**	**Mean usefulness rating (Range of usefulness ratings).**
Information about what trauma is.	100 (6)	3.67 (3-4)
Information about treatment for trauma	83.3 (5)	3.6 (3-4)
Grounding techniques	83.3 (5)	3.4 (3-4)
Relaxation techniques	66.7 (4)	3.5 (3-4)
Further information for staff	0	NA
Other (please state)	Trauma and the brain (psycho-education sheet) 16.7 (1)	4

Participants were also asked to indicate whether the amount of trauma based work they undertake had changed since the introduction of the resources. Out of the

nine respondents in the follow up condition, two said that their trauma based work had increased and seven said that their amount of trauma based work had stayed the same. Both individuals who stated their trauma based work had increased attributed this to the availability of the resources and training. One participant also said that the increase of trauma based work resulted from an increase in appropriate patients and also supervision.

Finally, participants were also given the opportunity to provide written feedback relating to their experience of using the resources. Participants highlighted the usefulness of the resources "to focus sessions" and when the staff member is "unsure how to move [the service user] forward". Participants also valued being able to give the service user handouts and one participant mentioned the benefit of using the resources as an "adjunct to specific trauma supervision". As a suggestion for improvement, one participant recommended having a separate hard copy of the resource file in a second service, where they primarily worked.

Phase two: Act

The second study phase indicated that staff confidence is higher after the introduction of the resources and there is also an increase in trauma work being carried out with service users. This suggests that these resources should be made available across the trust for other services to use, which may have a positive impact on recovery from C-PTSD for a greater number of people. It would also be useful to replicate this study with a larger sample size and a more stringent recruitment procedure that ensures retention across the data collection time points. It could then be established whether or not staff confidence increases over time with the introduction of the resources. It would also be interesting to investigate whether staff competence is altered by the introduction of staff resources and how to sustain any positive change in an environment where there is such a high level of staff change, as highlighted by the difficulty in retaining participants within this study. A further possible direction for future research could be to involve service users in improving the resources or in the development of additional resources that better meet their needs.

Discussion

This service improvement project aimed to increase staff confidence when doing phase one of C-PTSD work with service users. It was hoped that an increase in staff confidence would lead to staff choosing to do this type of work more often, thus increasing the opportunity for procedural learning of these skills (Bennett-Levy, 2006). Through semi structured focus groups, staff provided information about what they thought would help facilitate their trauma based work. This information was analysed and used to inform the production of a resource folder, which was available in hard copy format and electronically. Staff could refer to this resource for tools and information to support their trauma based work.

Results indicated that staff reported higher confidence on all assessed indices of trauma based work after the introduction of the resources, compared to staff who were asked to rate their confidence before the introduction of the resources. Staff also perceived their confidence in completing trauma based work as higher compared to how they predicted they would feel if the resources had not been made available. Confidence is not a direct indicator of competence so it is not possible to assert whether this approach was successful in improving skills through procedural learning (Bennett-Levy, 2006) however, staff members did report that the amount of trauma based work they had completed had either stayed the same or increased following the introduction of the resources, suggesting that some individuals experienced increased opportunity to improve their skills through procedural learning (Bennett-Levy, 2006) compared to before the introduction of the resources. The increase in staff confidence and the possible increase in access to this treatment for the service users could potentially facilitate recovery from C-PTSD in line with the three phase model recommended in trauma work (Cloitre et al., 2011; Cloitre et al., 2002; Herman, 1992).

Although the results of this study are largely positive, it is important to be cautious when interpreting the data. Due to the change in staff working for AWP and competing demands for staff time, the participants who took part at the baseline points were not the same individuals who responded at follow up, meaning it was not possible to calculate a change in confidence over time. Instead, this has been inferred from the

responses of different individuals before and after the introduction of the resources. In addition, we have no way to determine if there are any individual differences between the participants at various time points (e.g. job role) that may have influenced the results. Furthermore, there was a small sample size at each data collection point meaning it may be problematic to generalise these findings to a larger population or a different group of people. It is also important to consider the ethical implications of increasing non-specialist practitioner led trauma work in this way. There is no evidence to support the assumption that staff who have not been trained in specialist psychological therapies are able to provide an effective phase one intervention with service users. If it is the case that this approach is ineffective, then the service would incur additional costs to repeat the same phase of work with a second, specialist practitioner. This could increase the waiting time for the service user to be given the support they need and, in the worst case scenario, could be harmful to the service user's mental health. Further research is needed to ensure that providing phase one trauma work through non-specialist staff is effective before this approach is applied across additional clinical settings.

A second consideration when interpreting the results of this study is that confidence is being used a proxy for staff competence. One of the outcomes of the focus groups was that a lack of confidence acted as a barrier to staff engaging in trauma based work. Therefore, it was hoped that if staff members feel more confident in their trauma based work, they would then take more opportunities to practice these skills. In turn, this would hopefully increase procedural learning opportunities and therefore aid the acquisition and consolidation of learning for these skills (Bennett-Levy, 2006). However, this study did not directly measure whether this was the case. It is important for future research to investigate whether confidence predicts competence when providing phase one trauma interventions. If this is not the case, an increase in confidence could be hugely damaging as this could result in an increase in the provision of ineffective and therefore potentially harmful interventions.

Finally, staff may have over inflated their reporting of confidence post-introduction of resources and also over estimated their use of trauma based work,

either due to demand characteristics or an increase of focus and awareness on this area of their practice. On the other hand, it is also possible that participants underestimated how much trauma work that had completed because their declarative knowledge is not sufficiently developed for them to articulate clearly the work they have completed. It would have been helpful to complete an audit of trauma based work before and after the introduction of the resources to corroborate the findings of this study.

Despite the methodological limitations of this project, this research successfully demonstrates the helpfulness of resources in facilitating staff to complete phase one C-PTSD work. Staff expressed highly positive attitudes towards the resources. Actively involving staff through the use of focus groups ensured that the resulting product was consistent with staff needs and expectations. This may have facilitated the acceptance and uptake of these resources and contributed to the positive attitudes that staff expressed. Therefore, although the impact of using a focus group was not assessed within this study, the success of the project suggests that this is an important and helpful stage to include in the process of service development and change.

This study highlighted further room for improvement as only two out of nine staff reported an increase in their trauma based work following the introduction of the resources. This increase was attributed to training and supervision, as well as the availability of resources. This finding suggests that a multi-pronged approach may be helpful for facilitating an increase in trauma based work. However, it is also important to remember this project took place in a system where staff have a wide range of competing pressures, including statutory responsibilities such as mental health tribunals. Unfortunately, with so many conflicting demands, work such as phase one trauma techniques will rarely take priority.

The plan-do-study act cycle (Langley et al., 2009) provided a helpful structure for guiding the research process, especially within an NHS context where there were many competing demands for staff time and resources. Following this structure meant

that the research and improvement process could be divided into manageable stages, which allowed for flexibility within a dynamic setting. Furthermore, this model encourages continued progress. The end ‘act’ stage directly informs the next ‘plan’, meaning services can continuously improve and develop.

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Exploration of body perception and body dissatisfaction in young adults with Intellectual Disability

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Target journal: Journal of Intellectual Disability Research (see appendix H for instructions for authors).

Abstract

Background: People with intellectual disability (ID) are more likely to be overweight or obese compared to their peers, which fuels the need for effective healthy weight management programmes targeted at this population. In order to inform such programmes, more evidence is needed relating to how people with ID perceive their bodies.

Method: This study uses qualitative and quantitative methodology to explore body perception and body dissatisfaction in 40 young adults with ID compared to 48 individuals without ID. The Stunkard Figure Rating Scale was used to assess how participants perceived themselves, how they would like to look, and how they conceptualised underweight, healthy-weight and overweight. This rating scale was shown to be a valid and reliable measure when used with this population.

Results: Results show that young adults with ID tend to hold positive beliefs about their bodies. Females with ID are likely to perceive their bodies to be smaller than they are and neither males nor females report a desire for an altered body size. The results also suggest that individuals with ID understand what is meant by 'overweight', 'healthy-weight' and 'underweight' although these concepts are qualitatively different compared to those held by people without ID. Furthermore, individuals with ID are unable to apply these body size categories to themselves.

Conclusion: It is vital to consider these findings when designing healthy weight management programmes for people with ID. These individuals will need to be supported to understand how concepts of body size apply to themselves before they can move on to make positive choices about their weight management.

Key words: Body dissatisfaction, body perception, young adults.

Introduction

A growing literature documents the health inequalities experienced by people with Intellectual Disability (ID) compared to the general population (Allerton, Welch, & Emerson, 2011; Emerson, Baines, Allerton, & Welch, 2010). These disparities have been shown in both mortality and morbidity rates (Ouellette-Kuntz, 2005). One particular area of concern is the number of people with ID who are overweight or obese. Prevalence rates of overweight or obese individuals with ID vary depending on the country but range between 8.5% and 36%, which is consistently higher than the rates reported in the general population for the same countries (Grondhuis, & Aman, 2013; Rimmer, Yamaki, Lowry, Wang, & Vogel, 2010; Melville, Hamilton, Hankey, Miller & Boyle, 2007; Stancliffe, Lakin, Larson, Engler, Bershadsky, Taub, & Ticha, 2011). Being overweight or obese not only reduces an individual's quality of life (Hughes, Farewell, Harris, & Reilly, 2006) but is also associated with a wide range of secondary health problems such as coronary heart disease, type 2 diabetes, breast and colon cancers, gall stones and sleep apnoea (Craig & Mindell, 2011). This demonstrates the huge clinical importance of understanding eating behaviour and weight management in people with ID.

The developmental cognitive and weight concern model of eating behaviour cites body dissatisfaction as a key factor in influencing an individual's eating behaviour (appendix I; Ogden, 2012) and determines whether an individual is motivated to lose weight (Johnson, & Wardle, 2005; Neumark-Sztainer, Paxton, Hannan, Haines, & Story, 2006; Stice, 2002; Stice & Shaw, 2002). Higher levels of body dissatisfaction are often associated with unhealthy eating patterns including higher levels of restrained and emotional eating (Johnson, & Wardle, 2005) and higher levels of dieting, binge eating and reduced fruit and vegetable intake (Neumark-Sztainer, Paxton, Hannan, Haines, & Story, 2006).

Body dissatisfaction is conceptualised in several different ways. It can be thought of as a distorted body size estimation, where an individual perceives their body to be different from its actual size (body perception bias). This has been documented

consistently in the literature across males and females (Cohane, & Pope, 2001: Gila, Castro, Toro & Salamero, 1998) and is greater in individuals with an eating disorder (Gila et al, 1998). Although there is robust evidence for body perception bias in the general population, as yet, this has not been investigated in people with ID.

A second form of body dissatisfaction is having negative feelings and thoughts about one's own body such as wishing to be thinner or wishing to have more muscles (Cohane, & Pope, 2001, Gila et al., 1998). Again, this type of research is lacking in people with ID so it is unknown what types of body dissatisfaction are commonly experienced in this group.

A final form of body dissatisfaction is the discrepancy between how one perceives oneself and how one would ideally like to be (perceived-ideal discrepancy). Males often report a desire to be larger than they are and females report the wish to be thinner (Silberstein, Striegel-Moore, Timko & Rodin, 1988). This perceived-ideal discrepancy is considered a key contributor to an individual's eating behaviour and motivation to change their weight. It is unknown whether this discrepancy is present in people with ID.

The Stunkard Figure Rating Scale (SFRS) can be used to assess body dissatisfaction. This scale depicts drawings of nine male and nine female bodies, ranging in size from underweight to obese (appendix J; Stunkard, 2002; Stunkard, Sørensen, & Schulsinger, 1983). When using this scale, participants are asked to point to the figure that they believe represents their body and then point to the figure that represents how they would like to be to give an indication of perceived-ideal discrepancy. This measure has been shown to have strong psychometric properties when used with the general population but has not yet been used with people with ID (Stunkard, 2000).

Research in other areas has shown that people with ID sometimes struggle to apply generalised rules to themselves. For example, when asked "does everyone die?", 71% of people with ID correctly answered "yes" whereas only 42% answered "yes" to the question "will you die" and 55% of people answered "no" (McEvoy, 1989). Therefore, it would be interesting to know whether this sort of pattern is also apparent when referring to body image. For example, are people with ID able to identify an underweight, overweight and healthy body size but then unable to apply these categories accurately to themselves?

Based on the gaps in the literature identified above, the aims of this project are;

1. Explore the psychometric properties of the SFRS when used with people with ID.
2. Investigate whether people with ID have a concept for what is underweight, overweight and a healthy-weight and whether they can accurately apply these concepts to themselves.
3. Investigate whether people with ID have a body perception bias and compare this to people without ID.
4. Investigate whether people with ID report a perceived-ideal body discrepancy and compare this to people without ID.
5. Explore the themes of body dissatisfaction in people with ID.

Method

A mixed method design was used. Statistical Package for the Social Sciences (IBM SPSS Statistics, 22) was used for the quantitative analyses. All assumptions for parametric analyses were tested and non-parametric tests were used where appropriate. Content analysis was employed to further explore the themes of body dissatisfaction in people with ID. This method integrates qualitative and quantitative methodology. Content analysis was selected as this is appropriate to use in an inductive manner to build knowledge and understanding where no previous research has been conducted (Elo & Kyngäs, 2008). In this study, participants' responses were analysed to provide a preliminary description of body dissatisfaction in people with

intellectual disability. Furthermore, content analysis was particularly appropriate for this study as the categorised text could be summarised and then compared between the separate interview questions. This provided an opportunity to explore how participants perceived their own bodies compared to how they believed others perceived them.

Ethical approval for this project was granted by the University of Bath Ethics committee (see appendix K).

Measures

Weight, height and body mass index (BMI).

Each participant's BMI was calculated using weight and height and then categorised into healthy, underweight, overweight or obese according to Body Mass Index Classifications (World Health Organisation, 2015; table 1)

Table 1

BMI categories according to the World Health Organisation Classification system.

BMI	Category
<18.5	Underweight
18.5-24.9	Healthy weight
25.0-29.9	Overweight
>30.0	Obese

Background information questionnaire.

Background information was collected including age, gender, ethnic origin and whether or not the participant had a physical disability. It is possible that these personal characteristics influence an individual's perceptions and attitudes towards their body (Slade, 1994). Therefore, this information was collected so that the influence of these factors could be considered during data analysis.

The SFRS (appendix J); Stunkard et al, (1983).

Permission to use the SFRS was granted by the Director of the Center for Weight and Eating Disorders, where the scale was developed (appendix L). The SFRS was used in this study to assess participants' concept for different weight categories (underweight, overweight and healthy-weight), participants' perceived-ideal body discrepancy and participants' body perception bias. Participants used the figure pictures that were congruent with their sex. The validity of the SFRS is good, with a correlation coefficients of 0.67 between the SFRS and BMI and a correlation coefficient of 0.59 between the SFRS and weight (Stunkard, 2000). These correlation coefficients are high compared to those recorded for similar measures (Stunkard, 2000). The SFRS has also been shown to provide a valid representation of people's body size when measured by objective unbiased observers (Cardinal, Kaciroti & Lumeng, 2006). This study will be the first to document the use of this measure with people with ID.

Recruitment and consent

Eleven colleges that offered courses to young adults with ID and students without ID were approached. The course directors were contacted via email and/or phone and invited to take part in the study. They were provided with a rationale for the study and a brief description of the methodology. Two colleges (18%) opted to take part.

Private rooms within the colleges were used for data collection. The class teacher briefly spoke to the students to inform them about the study and then invited students to visit the research room one at a time if they wished to participate. It was left up to the discretion of the class teacher whether or not a learning support assistant accompanied the students to the research room.

Each student was greeted by the secondary researcher who went through the information sheet and gained consent. In accordance with the Mental Capacity Act

(Department of Health, 2005), potential participants were given all practical help available to enable them to make an informed choice whether or not to take part in the study. All potential participants with ID were asked a series of questions to check their comprehension to ensure that they were able to provide informed consent (appendix M). Although the length of time was not assessed formally, this process lasted between five and 30 minutes for each participant. 14% of potential participants were deemed to lack capacity to provide informed consent so were therefore not included in the study. These individuals still received a certificate and voucher to thank them for their time so that they were indistinguishable from their peers who had been able to take part.

Participants

A total of 40 young adults with ID and 48 individuals without ID took part in this study. All participants were aged between 16 and 25, which represents emerging adulthood (Arnett, 2000) and were attending an educational course within the South West of England. Table 2 shows the demographic information about the participants. Participants with a physical disability were not included in any analysis which required measures of height and weight.

Results

There is a significant difference in the ethnicity represented by the control group compared to the ID group. It was the intention to investigate whether ethnic origin influenced body perception and body dissatisfaction in people with ID. However, unfortunately, the sample size was too small to allow for this analysis

Table 2

Demographic characteristics of the ID group and the control group. Statistical analysis has been conducted to determine whether there are any significant differences between the two groups.

		ID group	Control group	Mann Whitney U/ /Likelihood Ratio/ X^2	*p* value
N		40	48		
WHO BMI category (%)	Underweight	15.4	10.4		
	Healthy weight	30.8	68.8	13.77	<0.01
	Overweight	28.2	14.6		
	Obese	25.6	6.3		
Mean age (years) (SD)		20.3 (2.4)	17.8 (1.5)	284.0	<0.01
Gender (% male)		50	57.5	0.49	0.48
Ethnicity (%)	White British	82.5	52.1		
	White other	0	6.3		
	White and black Caribbean	0	10.4		
	Other mixed ethnic background	0	4.2		
	Indian	5.0	4.2	21.26	=0.01
	African	12.5	12.5		
	Caribbean	0	4.2		
	Any other black background	0	2.1		
	Arab	0	4.2		

Validating the SFRS for use with people with ID

Inter-rater reliability.

The psychometric properties of the SFRS were assessed. Two researchers independently rated the participants on the SFRS according to which figure they thought was most representative of the participant's body shape. The primary researcher was a final year Clinical Psychologist in Training with a previous PhD completed within the intellectual disability field. The secondary researcher was an Assistant Psychologist working within a Community Learning Disability Team. The researchers' ratings were compared using Cohen's Kappa. The results indicated that there was a fair and significant level of agreement between the two raters for every item of the SFRS (Kappa= .284, $p<0.01$). A closer inspection of the data indicated that, although the ratings were significantly correlated, one researcher appeared to consistently score higher than the other, demonstrating a possible bias in one or both researchers (figure 1).

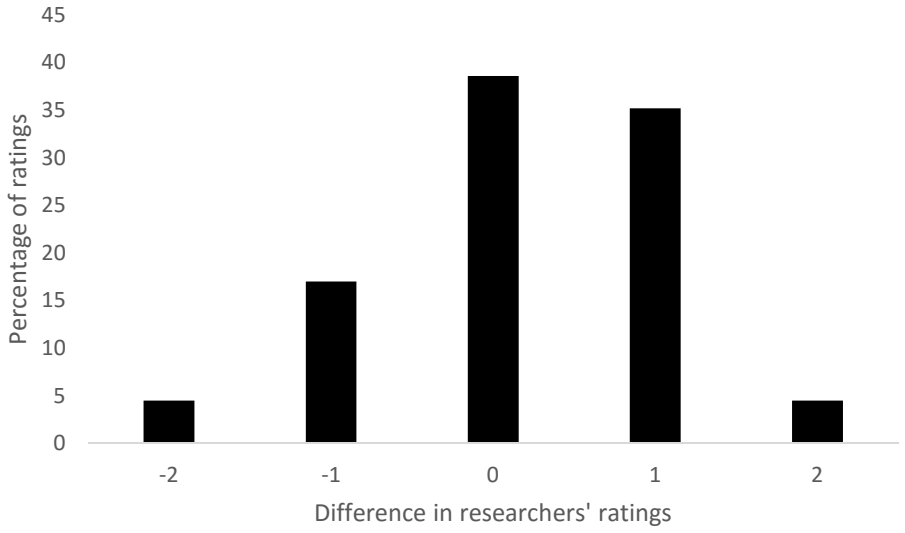

Figure 1. The difference between the two researchers' ratings on the 88 participants.

Research indicates that figure three on the SFRS represents an underweight individual (Bulik, Wade, Heath, Martin, Stunkard, et al., 2001, Lo, Ho, Mak, & Lam, 2012), figure four a healthy-weight (Must, Phillips, Stunkard & Naumova, 2002),

figure 5 an overweight individual (Lo et al., 2012, Must, et al., 2002), and figures 6-7 obese individuals (Bulik et al., 2001, Must et al., 2002). When the scores provided by each rater were grouped into these categories, the agreement between the two raters increased further to a moderate level of agreement (Kappa- 0.50, $p<0.01$) (Landis & Kock, 1977). This is in line with the work completed by Cardinal et al. (2006), which showed that the SFRS can be used by an objective observer to provide an accurate rating of body size.

Accuracy of using observers' rating on the SFRS to indicate BMI and BMI category.

Spearman's correlation coefficients were calculated between the mean of the two researcher's SFRS ratings and the participants' BMI. There was a strong, positive correlation between mean researcher SFRS rating and BMI in people with ID ($r_s(37) = .96$, $p < 0.01$) and those without a disability ($r_s(46) = .86$, $p < 0.01$). Fisher's exact tests (two tailed) were used to assess the association between researchers' mean ratings that were categorised according to the wider research literature (Bulik et al., 2001; Lo et al., 2012; Must et al., 2002) and the BMI classification index (WHO, 2015). Results indicated a significant association between researcher and WHO BMI classification for both the control ($p< 0.01$) and the ID groups ($p<0.01$).

Validity of SFRS when used by individuals with ID.

Data were analysed to determine whether participants had accurately identified a higher number figure as overweight compared to the figure they had identified as underweight. This provided a crude indication as to whether or not the participant understood the general logic of the SFRS. All participants in the control group and 33/40 (82.5%) of participants in the ID group were able to answer correctly. The following results are reported separately for the whole group of participants with ID and the subgroup of individuals who answered this screening question correctly.

Fisher's exact tests were used to compare the category of self-perceived body image, as reported by the participant (i.e., the BMI category of the figure they selected as representing themselves according to the research literature; four levels: underweight (figures one- three), healthy weight (figure four), overweight (figure five) and obese (figures 6 and above)), to their BMI category (WHO, 2015; four levels: underweight, healthy weight, overweight and obese). Results indicated that the ratings made by the control group were significantly associated with their actual BMI category ($p<0.01$). Ratings made by the whole ID group were not significantly associated with their actual BMI category ($p = 0.12$) whereas an analysis of the subgroup of participants with ID demonstrated that body ratings were significantly associated with BMI category ($p= 0.01$).

Do people with ID have a concept for underweight, overweight and healthy weight?

Participants were asked to indicate on the SFRS which figure they believed represents an underweight, overweight and healthy-weight individual. A number of Wilcoxon signed ranks tests were conducted. The lowest figure rating for an overweight individual was compared to the highest figure rating for a healthy individual and the lowest figure rating for a healthy individual was compared to the highest rating for an underweight body. Participants in the control group demonstrated clear categories for each of these body types, with significant differences between underweight (Median= 2) and healthy ratings (Median= 4) ($Z = -6.09$, $p <0.01$), and healthy-weight (Median = 4) and overweight ratings (Median= 7) ($Z= -6.12$, $p <0.01$).

Conversely, the Wilcoxon signed rank test results indicate that individuals with ID can only distinguish between healthy-weight (Median= 4) and overweight (Median= 8) (whole group: $Z= -5.23$, $p <0.01$; subgroup: $Z= -4.81$, $p<0.01$), but not healthy-weight (Median= 4) and underweight (Median= 2) (whole group: $Z= -0.18$, $p= 0.86$; subgroup: $Z= -1.26$, $p= 0.21$). This was investigated further by comparing the mean ratings of underweight, overweight and healthy-weight by participants with ID (see table 3). These ratings suggest that people with ID correctly conceptualise underweight as smaller than healthy-weight, and healthy-weight as smaller than

overweight. Furthermore, the mean ratings associated with each of these categories provided by people with ID more closely reflect the ratings previously reported in the literature compared to the control group (Bulik et al., 2001; Lo et al., 2012; Must et al., 2002) suggesting that people with ID do hold concepts for underweight, healthy weight and overweight.

Table 3

Mean SFRS figure ratings for underweight, healthy-weight and overweight.

	Mean highest underweight figure	Mean lowest healthy weight figure	Mean highest healthy weight figure	Mean lowest overweight figure
Control group	1.81	3.83	4.13	6.92
Subgroup ID group	2.64	3.33	3.61	7.64
ID group	3.83	3.73	4.0	7.78

Applying concepts of underweight, overweight and healthy weight to oneself

In order to assess whether people with ID apply generalised beliefs about body size to themselves, their verbal response for their perceived body size (i.e. if they stated they were underweight, overweight or healthy-weight) was applied to their picture rating of themselves. This was then compared to the ratings they gave when discussing body sizes in general. For example, if a participant verbally reported that they were a 'healthy-weight' and then indicated that they perceived themselves to be the number seven on the SFRS, the number seven would then be compared to the number that the participant provided when asked the general question 'which picture represents a healthy body'. Spearman's correlation coefficients were calculated between self-perceived body ratings and the rating given in general for the body shape the participant identified as (i.e. underweight, overweight or healthy weight). There was a non-significant correlation for both the whole group and subgroup of participants with ID (whole group: $r_s(35) = 0.03$ $p = 0.87$, subgroup: $r_s(31) = 0.06$ $p = 0.73$). This suggests that individuals with ID do not apply generalised rules for body size to themselves.

Body perception bias in people with ID compared to people without ID

Using the SFRS, participants were asked to indicate which figure best represented their body. This was compared to the mean researchers' ratings of the participant's body shape in order to provide a measure of body-perception bias. Wilcoxon signed rank tests indicated that individuals in the control group did not display a body perception bias (Z= -1.46, p= 0.15), which remained true even when the group was split according to gender (males: Z= -0.71, p= 0.48; females: Z= -1.48, p= 0.14).

In comparison, people with ID demonstrate a marginal body perception bias when the group is analysed as a whole (Z= -1.99, p= 0.046) but not when only the subgroup data was analysed (Z= -1.90, p= 0.06). When split according to gender for the whole group, the body perception bias was apparent in the females (Z= -2.73, p= 0.01) but not the males (Z= -0.02, p=0.99) and the same was found in the subgroup of participants with ID (females: Z= -2.39, p= 0.02; males: Z= -0.20, p=0.84). In both the whole group and subgroup of participants with ID, females were found to be perceiving themselves as significantly smaller than researchers had perceived them to be.

Perceived-ideal body discrepancy in people with ID compared to people without ID

Participants were asked to rate which figure represented their ideal self-image. The difference between perceived and ideal body provided a measure of perceived-ideal body discrepancy. A Wilcoxon Signed-rank test showed a significant difference between perceived body (median=4, range=1-7) and ideal body (median=4, range=2-5) in the control group ($Z = -2.29$, $p < 0.05$)**.** When split according to gender, the males did not show a significant difference between their perceived (median=4, range=1-7) and ideal body shape (median= 4, range= 3-5; Z=0.53, p= 0.56), whereas the females perceived body (median=4, range=3-7) was significantly larger than their ideal body shape (median=4, range= 2-5, Z=-2.72, p= 0.01).

The difference between perceived self (whole group: median = 4.0, range= 1-8; subgroup: median=4, range=1-8) and ideal self (whole group: median= 3.5, range= 1-8; subgroup: median=4, range=1-8) was not significant in people with ID **(**whole group: Z = -0.98, p = 0.33; subgroup: Z = -1.15, p = 0.25)**.** This was also the case when the results were split according to gender (whole group male: Z=-0.46, *p*= 0.65: whole group female: Z= -0.57, *p*= 0.57; subgroup male; Z= -0.87, *p*= 0.39 Subgroup female Z=-0.63, *p*=0.53). This suggests that people with ID have lower levels of perceived-ideal body discrepancy compared to their peers.

Exploring the themes of body dissatisfaction in people with ID.

Participants with ID were asked a series of open questions relating to how they feel about their bodies (appendix N). The answers resulting from these questions were analysed using content analysis in order to examine trends and relationships in the responses. The primary and secondary researchers independently completed the content analysis on the entirety of the data and then met to establish a consensus in the themes. There was 100% agreement of the themes identified by the two researchers although in question two, differences were identified between whether these were categorised as major themes or subthemes. The primary researcher categorised the data into the major themes 'smaller' (subthemes: 'thinner' and weigh less') and 'bigger' (subthemes: 'weigh more', 'stronger/muscles' and 'taller'). In comparison, the secondary researcher grouped the themes into 'weight' (subthemes: weight more, weigh less and thinner), 'height' (subtheme: taller) and 'strength'. Through discussion, the primary researchers categorisations were selected as these more closely related to later themes identified in question five, meaning comparisons between the two questions would be easier. Table 4 shows the major and minor themes resulting from this analysis.

Table 4

The major themes and subthemes identified through content analysis exploring body perceptions in young adults with intellectual disability (n= 40).

	Major theme (Number of responses that fell into theme)	Subtheme (Number of responses that fell into theme)
Question 1: How do you feel about the way you look?	Positive (22)	Clean (1) Strong(1)
	Neutral (15)	Don't know (2)
	Negative (2)	
Question 2: Is there anything you would like to change about your body?	No (22)	Don't know (3) No identified change (19)
	Bigger (7)	Weigh more (3) Strong/muscles (3) Taller (1)
	Smaller (8)	Thinner (4) Weigh less (4)
	Healthy (1)	
Question 3: Why would you want to change that about your body?	Primary change (8)	Appearance (2) Health (6)
	Secondary reward (1)	Start new activity/ get something new(1)
	Circular- method to get slim (3)	
	Perception of others (3)	Romantic other (1) Bullies (2)
Question 4: What do other people think about the way you look?	Positive (14)	
	Neutral (20)	Don't know (10) Concrete statement about appearance (4)
	Negative (2)	
Question 5: Why might other people want to change the way they look?	Perception of others (3)	Romantic other (1) Bullies (1)
	Bigger (3) Smaller (3) Don't know (10) Comparison to others (1) Dissatisfaction with self (7) Health (5)	

The results from the first question show that the largest proportion of participants with ID viewed their bodies favourably (55%), responding with statements such as “good”, “brilliant” and “awesome”. 37.5% of participants provided neutral answers when asked how they viewed their bodies, such as “fine” and “alright”. Only two participants (5%) reported a negative view of their bodies, both stating “I don’t like it”.

When asked if there is anything that they would like to change about their bodies (question two), 55% of respondents answered that there was nothing they wanted to change, 64% of whom were the participants who responded that they were happy with their bodies. The most common identified change, endorsed by 20% of participants related to wanting a smaller body, either “being slimmer” or to “lose weight”. 17.5% of participants stated that they wanted a bigger body. This divided into further subthemes including wanting bigger muscles/being stronger, wanting to be taller and wanting to increase in weight.

When asked why they would like to change their bodies in that way, the most common responses could be themed as a primary reward including a change in appearance, which was suggested by 5% of participants, such as “not to have a belly” and a change in health, which was given as a reason by 15% of respondents. Answers coded according to this theme included “to be healthier” and “because I’m getting out of breath and it has caused damage to my knees”. The perceptions of others were also cited as a reason by 7.5% of participants, including the views of romantic others; “to go on a TV show like *take me out* when you’re single” or “for my girlfriend”, and the views of bullies; “because I’ve been getting picked on” and “so if someone big came up to me, I would be tough and could fight them off”. Finally, a number of participants provided answers that appeared to give details about how to achieve the desired change, rather than a reason why. For example, one participant responded; “healthy food, stop eating bad food” and another said “so I can get more active”.

The forth question related to what the participant thought other people felt about their appearance. The themes to this answer mirrored those from the first question; either falling into positive (35%), negative (5%) or neutral (50%). Positive answers included statements such as “look cool”, “amazing” and “beautiful” and negative answers included “they say I look ill” and “some horrible”. Many of the participants who believed that others viewed them in a positive way, also felt positive about themselves (11/14; 79%) whereas this was not the case for the participants who either viewed themselves in a negative way or felt that other people viewed them negatively. The largest proportion of participants responded in a neutral way, which also included answering “I don’t know”, which accounted for half of the neutral answers.

The final question asked participants to think about other people and state why others may choose to change something about their bodies. The most common answer was “I don’t know”, which accounted for 25% of responses. Second to this was the suggestion that the person was dissatisfied with their appearance for some reason (17.5%), such as “because they’re not happy with how they look” or “because they don’t like how they look- just their personality”. As with question two, there were also themes around wanting to be smaller (7.5%) and bigger (7.5%). In both of these cases, there was one participant (2.5%) whose response from question two directly matched their response to question five. Another theme to be identified from the fifth question was citing health as a reason for another person wanting to change their body (12.5%). These responses included answers such as “not healthy”, “because they don’t want to get obese” and “so they keep fit”.

Discussion

Overview.

The aim of this research was to provide an initial investigation into body perception and body dissatisfaction in people with ID, in order to inform this aspect of the developmental, cognitive and weight concern model of eating behaviour for this population group. Content analysis was used to explore the themes reported by

individuals with ID about how they feel about their bodies. A range of quantitative analyses were conducted to test the psychometric properties of the SFRS when used with people with ID and to establish whether people with ID experience body perception bias and ideal-self discrepancy.

Validating the SFRS.

The SFRS is a widely used tool for assessing body perception and body dissatisfaction. Before this study, it had not been used with people with ID. The results of this study suggest that the SFRS can be used as a reliable and valid measure of BMI with people in the general population when ratings are made by an objective observer or by the individual themselves. This is only the case with people with ID if they have demonstrated a basic understanding of the SFRS first. This can be assessed by checking if the individual understands that an overweight body is indicated by a higher number figure compared to an underweight body. Interestingly, a closer inspection of the data suggested that, although the raters demonstrated a relational congruence (i.e. if presented with two bodies, they would order them in the same way) one rater would frequently and consistently rate people higher on the SFRS compared to the second rater. This suggests that objective observers may be susceptible to their own biases when rating other people. In order to maximise the validity of the SFRS, it would be advisable to have a period of training where raters are informed of participants' BMIs in order to identify their own perception biases and learn to counter the influence of these beliefs.

Having a concept for underweight, healthy weight and overweight.

By using the SFRS, it was demonstrated that people with ID do seem to have a concept for underweight, healthy-weight and overweight although this appears qualitatively different to how their peers without ID perceive these body categories. The results of this study suggest that people without ID have a more extreme view of underweight compared to people with ID. Also, people with ID appear to accept smaller body sizes as healthy compared to their peers without ID. Furthermore, people with ID appear to conceptualise overweight as larger than people without ID. Further

research is warranted to investigate the cause and implications of these body shape conceptualisations. This finding may suggest that people with ID are less susceptible to societal pressures, which promote thinness and discourage being overweight, resulting in a less extreme and a more accurate view of what is underweight. This finding might also indicate that people with ID conceptualise overweight as being bigger than how their peers without ID view this body category. This may reflect differences in the prevalence of overweightness and obesity in people with ID, which may skew what is perceived as 'normal' and therefore what is healthy versus overweight.

Applying the concept of underweight, healthy weight and overweight to oneself.

Even though people with ID understand the concept of underweight, healthy-weight and overweight in general terms, they did not appear to apply these categories accurately to themselves. This is important when designing weight management programmes as it may be necessary to first ensure that the individual recognises their weight status before supporting them to make healthy choices. For example, if an individual learns the importance of diet for overweight people, they would then need to identify themselves as being overweight to recognise the importance of applying this health choice themselves.

Body perception bias.

Individuals in the control group were able to accurately recognise their body shape on the SFRS. However, females with ID significantly underestimated their body size. This contradicts what would be expected according to the extant literature, which states that females typically perceive themselves to be larger than they are (Cohane, & Pope, 2001: Gilaet al., 1998). One possibility is that females were answering in accordance to what they thought the researcher wanted to hear (i.e. demand characteristics) although, if this was the case, you would expect the same result for the male participants with ID. Further research is needed to explore this area in more detail to establish what the likely cause of this finding is. Understanding body-perception

bias in people with ID is vital for informing weight management groups, especially for females with ID.

Perceived-ideal body discrepancy.

Individuals with ID do not express the same perceived-ideal body discrepancy as is seen in the general population. This may link to lower levels of distress associated with being unhappy with one's own body, and also protect people from unhealthy eating practices such as binging and emotional eating (Johnson, & Wardle, 2005; Neumark-Sztainer et al, 2006). However, this may also remove a motivational factor for making positive changes if an individual is not a healthy weight.

Content analysis of body dissatisfaction in people with ID.

The content analysis suggested that the majority of people with ID are satisfied with their bodies and believed that others also perceive their bodies favourably. This further supports the notion that individuals with ID may lack the motivational influence of feeling negatively towards themselves or believing that others are viewing them critically.

Limitations and future research directions.

There were a number of limitation with this study that should be considered when interpreting the data. First, the order of the questions relating to body size categories (i.e. which body is overweight, underweight or health weight) was not randomised. It may be the case that there was an order effect to results that were obtained. Also, participants were asked these questions after being asked to rate their perceived body on the SFRS. Participants may have altered their later answers based on previous responses, for instance, if they did not want to be seen to identifying as underweight or overweight. A further limitation was that, due to the nature of the SFRS, individuals who positioned themselves on the far ends of the scale were restricted in their responses for any perceived-ideal body discrepancy. For example, if an individual rated themselves as a '1', they would be unable to provide a response

that would indicate they would want to be smaller than they currently view themselves to be. Finally, the ethnic diversity of this study was limited and the sample size was too small to look for any differences between people from different cultural backgrounds. This could be an interesting avenue for future research as it may be that different cultural ideals influence body dissatisfaction in different ways.

Clinical implications.

This research is an important first step in exploring the factors that may make healthy weight management interventions particularly difficult for people with ID. First, in order to promote healthy choices, females would need to be educated in order to perceive themselves accurately, rather than being influenced by their bias to view themselves as smaller than they are. Then, both males and females would need support to understand how to apply body categories to themselves. Only through integration of these levels of understanding could an individual progress to a point of making the correct health choices for their body. Even then, it may be difficult to instil motivation for change as one of the most common drives for weight management is a perceived-ideal body discrepancy (Johnson, & Wardle, 2005; Neumark-Sztainer et al.,2006; Stice, 2002; Stice & Shaw, 2002), which people with ID have been shown not to have. It should not be a target of interventions to promote body dissatisfaction, but, if body dissatisfaction is not present, interventions need to focus on building alternative sources of motivation for healthy weight management.

Wider research implications.

This exploratory study identifies a number of interesting differences between body dissatisfaction in people with ID compared to those without. It is important that replication studies are conducted in order to strengthen the confidence that can be held in relation to these findings.

This study also makes a conceptual contribution to wider psychological theories. For example, the norm theory postulates that each experience provokes the

retrieval of memories or the construction of mental simulations that are then used to provide a reference for the current event. This then allows inferences, predictions or judgements to be made about the current experience (Manstead, Hewstone, Fiske, Hogg, Reis & Semin, 1995). For example, according to this theory, when making the judgement about own body size and 'overweightness', an individual will evaluate their body in reference to their schema (norm) for overweight bodies. Specific examples of overweight bodies will be brought to mind and the individual will also imagine fictional overweight bodies, which fit their schematic representation of this concept. Their body will then be evaluated according to this specific frame of reference (Kahneman & Miller, 1986). This may be particularly relevant to understanding how individuals with ID apply the concept of overweightness to themselves. Given that the prevalence of overweightness and obesity is higher in people with ID, it may be that the remembered and imagined examples of overweight individuals in this population are larger than those activated by individuals without ID. Therefore, when compared to these extremely large representations of 'overweightness', the individual will ID may judge themselves as different to this norm, and therefore not apply the concept of 'overweight' to themselves. This will then have clinical implications as individuals may fail to engage in weight management interventions if they do not perceive themselves as having a problem and are therefore unmotivated to change their behaviour. This lack of engagement and motivation due to not recognising oneself as having a problem has been found in other areas of clinical psychology such as substance misuse in people with ID (Taggart et al. 2007).

This study begins to address the relative dearth of research with people with ID compared to the general population in the area of body perception and body dissatisfaction. One of the reasons why there may be such a lack of research with this population group is because of the difficulties with recruitment and ensuring that participants are able to provide informed consent to take part. This study uses a comprehension checklist as a unique approach to assessing capacity for participation in research. Although this was a time-intensive approach, it was shown to be a successful and ethically robust solution to this challenge. However, it was often the case that individuals who were found to lack capacity had already spent significant lengths of time with the researchers, frequently more than their peers who were able

to provide consent. This was one of the reasons why it was deemed appropriate for these individuals to receive the financial reward intended for participants. As 14% of individuals assessed were deemed unable to provide informed consent, this is potentially a costly approach to recruitment, both in terms of finances and time. This expense is then exacerbated as some of the participants who were able to provide informed consent are then still not able to fully engage in the research due to their cognitive difficulties. These challenges should not act as barriers to research in this area, but should be considered when designing research protocol with people with ID.

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Executive summary

People with intellectual disability are more likely to be overweight or obese compared to people in the general population. This has a range of serious negative health implications and highlights the clinical and ethical need to support these individuals to achieve and sustain a healthy weight. Despite this, there is currently a dearth of research focussed on this topic. In comparison, the research literature is relative well established in the general population, which provides a helpful template for beginning work in this area for people with intellectual disability.

The developmental model of eating behaviour suggests that body dissatisfaction is a key influential factor in determining an individual's food choices. Body dissatisfaction refers to several different phenomena. First, this refers to a body perception discrepancy where an individual perceives themselves inaccurately, either as bigger or smaller than they really are. This is most commonly discussed in relation to people with eating disorders although the literature states that this form of body dissatisfaction is evident in males and females in the general population. The second form of body dissatisfaction is if an individual would choose to alter their body size or shape if they could. Throughout the current report, this form of body dissatisfaction is referred to as perceived-ideal discrepancy. Finally, body dissatisfaction describes when an individual holds negative thoughts and feelings about their bodies.

This current study begins to address the disparity between what is known in the general population about body dissatisfaction compared to the evidence base for people with intellectual disability. A mixed method approach was used to explore each of the three types of body dissatisfaction within a sample of 40 young adults with intellectual disability compared to their peers without an intellectual disability.

The first stage of the research was to investigate whether the Stunkard Figure Rating Scale (SFRS) is a valid measure when used with people with intellectual disability. This scale depicts the pencil outline of nine female figures and nine male figures gradually increasing in size to represent underweight individuals ranging up to

overweight and obese individuals. This scale has been shown to provide accurate estimates of body mass index (BMI) when ratings are made by an objective observers and can be used to indicate the self-perceived body size and ideal body size in people without intellectual disability. This study showed that some people with intellectual disability are able to use this scale to accurately indicate the figure most representative of their BMI whereas other individuals were not able to understand how the scale worked. Because of this, the results for the remainder of the study were separated according to whether or not the individual understood the SFRS.

Participants were asked to point to the picture on the SFRS that they thought represented their body size, their ideal body size and the pictures that represented an underweight, overweight and healthy weight individual in general. The responses to these questions revealed that people with intellectual disability understand what is meant by 'healthy weight', 'overweight' and 'underweight', but these concepts are qualitatively different compared to those held by people without intellectual disability. The findings also showed that individuals with intellectual disability do not apply these body concepts (underweight, healthy weight and overweight) to themselves, even if they understand how to apply these to other people. The results also indicated that females with intellectual disability showed a significant body perception discrepancy and viewed themselves as smaller than they really were, which is the opposite to what would be expected based on research in the general population. Males with intellectual disability were found to not have a body perception bias. Finally, the results also demonstrated that neither males nor females with intellectual disability have a significant perceived-ideal body discrepancy, indicating that they are relatively happy with their bodies compared to their peers without an intellectual disability.

Content analysis was used to further explore the themes of body dissatisfaction in people with intellectual disability. This analysis supported the other findings that, generally, most people with intellectual disability view their bodies favourably. The analysis also revealed that they believe other people view them in the same positive or neutral way. For those individuals who did want to change their bodies, the most

commonly cited reasons related to desiring a change in appearance or wanting to be healthier.

These findings are an important first step in informing a psychological model of eating behaviour in people with intellectual disability, which can then be used to inform psychological interventions for weight management in this population.

Accessible summary

More people who have a learning disability are overweight than people without a learning disability. This can be a problem because it means that they might get sick and need help from a doctor. We wanted to help people with a learning disability to look after their bodies. We needed to know more about how people think about their bodies so that we could help. We found out that people with a learning disability find it hard to know how big their bodies are. We also found out that people with a learning disability are happy with how they look and don't want to change anything. It is important to think about this when we help people to look after their bodies.

Connecting Narrative

Throughout the course of training, I have completed three separate research projects and five case studies. The research projects were; a main research project (MRP), a service improvement project (SIP) and a literature review. The challenge of completing these pieces of work alongside clinical placements and teaching has been both demanding and rewarding.

My MRP most closely reflects the work that I had done previously as a doctoral researcher and was therefore the project I felt most confident about. This was also the project that I was initially most invested in. I was keen to continue my work as a researcher and eager to ensure that this project was well thought out and well conducted. As a cohort, we were encouraged to embrace new areas/topics of research for each of our projects and not necessarily stick to what we were already familiar with. The freedom to choose *any* topic for my MRP caused a mixture of responses. I was excited as well as being intimidated and overwhelmed. It is perhaps unsurprising that these emotions led me to select a research project with people with intellectual disability, which is the area I had experience in and was passionate about, and also where I felt most at home. This helped to ease the more uncomfortable emotions I was experiencing but also allowed me to embrace a bit of novelty as I selected a topic area that I hadn't yet researched. I wanted to investigate the motivation orientation (i.e. internal versus external motivation) of people with intellectual disability to lose weight.

I invested a lot of time researching the topic of motivation and weight loss in people with intellectual disability and wrote a research proposal. My plan was to recruit individuals with intellectual disability who had enrolled in a weight loss group, asses their motivation and then follow their weight loss progress. However, the group that I had planned to follow up got decommissioned, which put a stop to that plan. This experience demonstrated one of the barriers to completing research within the NHS, which is currently in a state of massive flux and unpredictability. Following this

experience, I chose to design a new study, which eliminated the reliance on NHS services.

My second choice of MRP topic was still in the same broad area, but this time, focussed on a different factor that could influence weight loss in people with intellectual disability. Although a lot is known about this topic in the general population, research is really lacking in relation to people with an intellectual disability. Again, the experience of having no limits on the choice of topic was almost paralysing as it was so difficult to focus my reading and attention adequately to come to a decision. With the help of a mind mapping session with two lecturers, I eventually settled on the idea of looking at body dissatisfaction in people with intellectual disability. As I had already passed the course requirements for submitting a research proposal due to the first MRP that fell through, I did not have to submit anything else to the university in relation to my MRP. Although I was initially relieved to not have to do additional work, this also left me feeling alone and uneasy as there was no reassurance that what I had decided to do would fit with course expectations. However, there wasn't the time to wallow in these feelings of insecurity and I just had to proceed with the project and trust mine and my project supervisor's decision.

Following the write up of the research protocol and ethics submission, the next step for my MRP was recruiting participants. I had decided to recruit participants from colleges as it was felt that these individuals would be a more homogenous group compared to people accessing mental health services (and this also meant that I could avoid NHS ethics!). I set about phoning and emailing colleges across the South West of England who offered an extended education course for people with intellectual disability, asking for interest in taking part in this research study. I was surprised by the lack of uptake. This may reflect the current climate in education services, which largely mirrors what is going on within the NHS. Teachers are so inundated with endless additional responsibilities, that this undoubtedly leaves little space for considering anything additional to their work load, such as participation in research. However understandable this position is, I also find it upsetting and frustrating. I think I have a habit of assuming that other people share my views in relation to research and

can immediately see the value and importance of pursuing this. For me, this is especially pertinent for people with intellectual disability, who are repeatedly underrepresented or neglected in research. Research could help to inform services, help to address the disparity between knowledge of how to support people with intellectual disability compared to the general population and help to address the inequalities faced by people with intellectual disability. Given the possible positive influence of research within this population, it is upsetting that those who are in a position to facilitate research are often indifferent or worse, create barriers which perpetuates the lack of research in this area. Or, those who do want to facilitate research, are restricted from doing so because of the other demands of their role.

After extensive effort to recruit colleges to the study, I managed to get two colleges on board. At this point, I became aware of yet another barrier to research with this population and an example of a mismatch between the world of research and an educational setting. I had specifically designed my research project to be with people aged 16+ as the mental capacity act clearly states that, at this age, people are responsible for providing their own consent to take part in research. However, within an educational setting, this was questioned and one college requested that parental permission was also sought. Extensive effort had been made to ensure that individuals participating in the research had provided informed consent before any data was collected. Therefore, including parents in the process directly undermined the individual's rights to choose whether or not to take part. The college's request was initially viewed as a consequence of the educational setting, where individuals are perceived as children until past the age of 16. However, it later transpired that this request for parental permission only applied to the students with an intellectual disability. This request was undoubtedly made with the best interest of the individuals with intellectual disability in mind. However, in reality, this effort to protect the individuals with intellectual disability directly resulted in discrimination where the views of the individual were potentially undermined and overruled by parents. This contravenes the guidelines set out by the mental capacity act and put me in an impossible situation. I *had to* incorporate parental permission into my protocol as, without this, I would not have been able to recruit any participants within the time available. However, this went against everything I believe in terms of not

discriminating against people with intellectual disability and ensuring they have the same rights and opportunities as their peers without a disability. In future research, I plan to investigate the barriers to conducting research with people with intellectual disability, including this unhelpful overprotectiveness and a misunderstanding of capacity laws.

My literature review also attempted to address the discrepancy between what is known in the general population compared to people with disabilities. The aim of my literature review was to determine whether the widely accepted definition of domestic abuse adequately captured the experiences of victims with disabilities. This could potentially have huge clinical and research implications. Without an appropriate definition, research is inevitably going to be flawed as there is no shared concept for domestic abuse, which can then be investigated. Without an adequate definition of abuse that speaks to the experiences of people with disabilities, services will fail to meet the needs of these individuals. Although I was adamant that this was an important and appropriate topic for a literature review, I found that this conflicted with course requirements. As with all research projects, the course requested that the literature review be based on, or inform a theoretical model, and argued that my proposed review was more aligned to a political rather than psychological orientation. I feel that these requirements do not take into account the current state of research with people with intellectual disability, or any other research area/topic that is still in its infancy. The course appears to be biased towards population groups and research areas that are already fairly well established, for which a theoretical account is already available. It is a shame that the course doesn't appear to promote or facilitate research that has not yet reached this point.

My SIP better suited the requirements of the course. This focussed on producing resources for staff to use during trauma focussed work with adults in a mental health service. There are already established theories of the skill acquisition in staff and an emerging literature base for working with people with complex trauma. This project also suited the practical set- up of the course. We were allocated very little time for research projects within our work hours. Therefore, projects had to be

completed in a piecemeal way, as and when time became available. My SIP consisted of many small, independent stages, which perfectly suited this way of working. I imagine that training may closely mirror what happens in general clinical practice, where competing demands mean that research is not prioritised. This will be an important consideration when I design research projects in the future that will be completed alongside clinical work. However, it was also apparent how quickly all of my projects progressed in the final year of training compared to the previous years. In the third year, we were given one research day a week. This allowed me to plan my work load and meant that I could progress with all projects, including those that required a more concentrated approach. I will also use this knowledge when considering my job plan and ensure that I specifically allocate time to research once I am qualified.

Finally, throughout training, I completed five case studies. It was unclear whether these were considered an academic or clinical task. This presented difficulties when negotiating when these should be written and generally resulted with the bulk of the work reluctantly being done in my own, personal time. The case studies each summarised a piece of clinical work. I often found that the literature review I completed during the write-up of the case study provided information that would have been helpful during the clinical work. This reminded me of the value of referring to research knowledge and highlighted the difficulty of maintaining a truly scientific practitioner approach when there are so many competing demands, which leave little time for reviewing the literature. However, keeping up to date on current research should potentially save time in the long run as evidence based interventions should be more effective. Therefore, I endeavour to be mindful of this when I enter my qualified work and ensure that I make time for keeping up to date on research developments.

These various research projects have provided me with experience in a wide range of topic areas. Although this is interesting, I feel that it is not the most efficient approach to take when there is so little time and so many competing demands. I feel that it makes more sense to focus on one topic area and become expert on this. I believe it is better to have a narrow focus and do this work well, rather than stretching time

and resources, ultimately resulting in lower quality research with less informative outcomes.

Appendix A. Author instructions for the Journal of Family Violence

Manuscript style

The entire manuscript should adhere to APA 6th edition standards including: Times New Roman 12 pt. font, 1” all around page margins, with a page header at ½" and entire manuscript should be double spaced, left aligned with .5” first line indents. Quotations, references, figure-caption list, and tables must also adhere to APA 6th edition guidelines. With quotations of 40 or more words, DO NOT use quotation marks. Set off the quotation in Block style format indented ½". Number all pages consecutively with Arabic numerals, with the title page being page 1 and include a running head on all pages. The suggested running head should be less than 40 characters (including spaces) and should comprise the article title or an abbreviated version thereof.

A title page should be uploaded as the first page of the manuscript and should include only the title of the article. Do not include author's name or author's affiliation or other identifying names since the manuscripts undergo anonymous reviews. An abstract is to be provided, and should be no more than 150 words. Abstract should be flush left and left-aligned. A list of 4−8 key words is to be provided directly below the abstract. Key words should express the precise content of the manuscript, as they are used for indexing purposes.
List references alphabetically at the end of the paper and refer to them in the text by name and year in parentheses. Where there are six or more authors, only the first author’s name is given in the text, followed by et al., unless there are more than two references with the same author surname and same year. In this case, list as many others as needed (usually no more than two or three) to indicate which reference you are referring to followed by et al.

Appendix B. Author instructions for the Journal of Cognitive and Behavioural Practice

Article structure

Subdivision - unnumbered sections

Divide your article into clearly defined sections. Each subsection is given a brief heading. Each heading should appear on its own separate line. Subsections should be used as much as possible when cross-referencing text: refer to the subsection by heading as opposed to simply 'the text'.

If you are submitting original research, the structure of your paper should typically reflect the stages of the research process:

Introduction
Method
Results
Discussion

However, as contributions to this journal take various forms (including empirical research, review articles, methodological papers, and case studies), authors are urged to organize their manuscripts in ways that make sense to their particular article type.

A detailed description of all possible sections is shown below.

Introduction

State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

Methods

Provide sufficient detail to allow the work to be reproduced. Methods already published should be indicated by a reference: only relevant modifications should be described.

Results

Results should be clear and concise.

Discussion

This should explore the significance of the results of the work, not repeat them. Avoid extensive citations and discussion of published literature.

Conclusions

The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section.

Essential title page information

• ***Title.*** Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.
• ***Author names and affiliations.*** Please clearly indicate the given name(s) and family

name(s) of each author and check that all names are accurately spelled. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.

• ***Corresponding author.*** Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. **Ensure that the e-mail address is given and that contact details are kept up to date by the corresponding author.**

• ***Present/permanent address.*** If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

Appendix C. Confirmation of ethical approval for the service improvement project.

Avon and Wiltshire NHS
Mental Health Partnership NHS Trust

Avon and Wiltshire Mental Health Partnership AWP Trust

AWP Quality Academy

Blackberry Centre

Manor Road

Fishponds

BS16 2EW

0117 378 4238/ 07825 725296

Dr. Kate Eden
Clinical Psychologist in Training
Avon Forensic Community Learning Disabilities Team
Withywood Centre
Bristol

Date: 8th January 2015

Dear Kate Eden

Increasing staff confidence and implementation of trauma therapy skills; a service improvement project.

AWP Reference: 2014.E025 Eden

This letter is to confirm that your evaluation is now approved and also provides you with our reference number.

If you do need any further support or information, please contact us using the contact details above, quoting our reference number for your study.

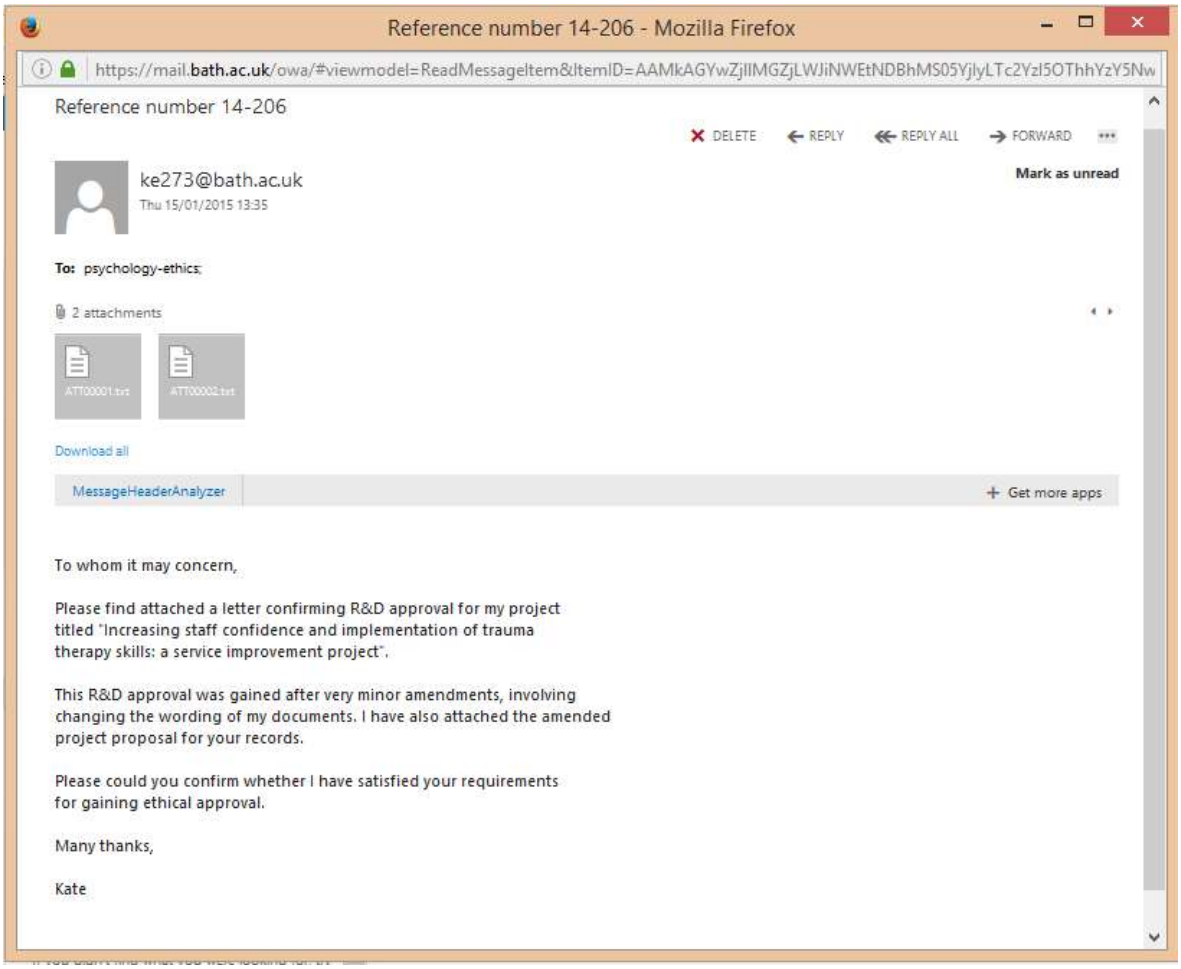
The importance of disseminating all evaluation work cannot be over emphasised. It is only by sharing our learning that we can improve services across AWP. For this reason, the

findings of all evaluation work should be reported to the Evaluation team via email. The team will champion the results of service evaluations, and work with evaluators to ensure those results are disseminated and acted upon, and that the results of evaluations are reflected in future service delivery. The team will also work with evaluators to produce publications for the public domain.

I very much look forward to receiving the results of your evaluation in due course.

Yours sincerely,

Janet Brandling



Appendix D1. Interview schedule for service improvement project focus group one.

1. What element of trauma focussed work would resources be helpful for?

2. Where would trauma work most likely take place?

3. Do you know of any resources that staff in your team, or yourselves tend to use when doing trauma focussed work?

4. What sort of information would be most useful to include in these resources?

5. Is there anything else that either of you would like to add?

Appendix D2: Interview schedule for focus group two.

1. When you hear the term trauma, what sort of things to you all think of?

2. So are there any sort of particular people that you might expect to associate trauma with?

3. Is there anything else that people think of when they think of trauma?

4. What do you think trauma focussed work would involve?

5. We plan to make resources to help staff when doing trauma focussed work. Do you know of any resources that are available currently?

6. What have you found helpful about the resources that you have used before?

7. What have you found unhelpful about the resources you have used before?

8. What sort of information do you think would be helpful to include in the resources that we will be developing?

9. Is there anything that anyone wants to add about anything that we have talked about today?

Appendix E1: Contents of the resource pack.

Contents

(Please update this as you add more resources into this folder and the shared drive resource folder)

	Information and education about trauma				
	PTSD and Complex PTSD: Signs and Symptoms				
	Why are some people more vulnerable to developing PTSD than others?				
	What does trauma look like?				
	Helpful and unhelpful coping strategies				
	Dual diagnosis				
	Trauma and the brain				
	Using the brain to understand the rationale for psychological therapy for PTSD				
	Treatment for PTSD				
		Care pathway for PTSD			
		Safety nets- a metaphor for trauma based work			
		What is Trauma focussed CBT			
		What is EMDR			
		Maslow's Hierarchy of needs			
	Phase one techniques				
	Grounding techniques (to be used for people with flashbacks, nightmares and/or dissociation)				
		Background information for staff			
		Background information for service users			
		Coping with flashbacks handout for service users			
		Flashback halting protocol			
		Cognitive awareness grounding exercise			
		The 5,4,3,2,1 game			
		Nightmare exposure and rescripting			
	'Dealing with distress' booklet including: (decide with the service user what sections may be helpful)				
		Distress tolerance			
			IMPROVE AND ACCEPT		
			Distraction and Pleasurable Activities		
			Relaxation		
			Safe place visualisation		
			Positive affirmations		
		Mindfulness			
			WISE mind		
			Wise Inner Advisor Visualisation		
			Colour Breathing		
		Emotion Regulation			

Appendix E1: Contents of the resource pack.

				Opposite Action, Opposite Emotion, PLEASE Master
				Emotions and their associated thoughts and reactions
				Dealing with Negative Emotions-quick reference
				Dealing with Distress Worksheets
				Questions to ask when you're distressed
				Fact or Opinion
			Interpersonal Effectiveness	
				DEAR MAN & GIVE
				FAST
				Assertiveness
				Communication styles-Passive, Assertive and Aggressive
				Handling criticism
				Saying No
				Telling others what we want
				STOPP- 5 steps to deal with distressing situations
				The Helicopter View
				Positive Steps to Wellbeing
		Relaxation techniques		
		Colour breathing		
		Relaxed breathing		
		Progressive muscle relaxation		
		Mindful breathing		
		Imagery		
			Relaxing safe place	
			Wise inner advisor	
			Confident, Competent, Content	
			Goal rehearsal/ achieving future success	
			Colour visualisation and breathing	
			Image manipulation and rescripting	
			Positive imagery for depression	
	Supporting Staff			
	Looking after yourself			
	"Vicarious Trauma" information sheet			
	Resources and information			
	Resources and information reference sheet			
	How to ask about trauma			

Appendix E2: Example from resource pack; the 5, 4,3,2,1 game

The 54321 game

Name 5 things you can see in the room with you.

Name 4 things you can feel (“chair on my back” or “feet on floor”)

Name 3 things you can hear right now (“fingers tapping on keyboard” or “tv”)

Name 2 things you can smell right now (or, 2 things you like the smell of)

Name 1 good thing about yourself

Appendix E3: Example from resource pack; looking after yourself

Looking after yourself

Working with people with trauma can be highly challenging. This area of work is likely to involve witnessing pain and distress in survivors of trauma and may also involve hearing the narratives of traumatic experiences. This may result in **vicarious trauma** in staff, which is a state of tension or emotional distress directly resulting from baring witness to an individual's trauma story. For more information of the signs or symptoms of vicarious trauma, please see the information sheet titled "Vicarious Trauma".

It is essential that you look after yourself when working with people with trauma. Some useful ways to do this are:

- **Prioritise supervision.** Both formal and informal supervision are vital when working with people who have experienced trauma. Supervision should not only be seen as a time to discuss the contents of the trauma focussed work, but also an opportunity to monitor the wellbeing of the staff member and ensure that they are receiving sufficient support. You may find it helpful to put this on your supervision agenda.

- **Consider a caseload mix.** It is important that you don't feel overloaded by trauma focussed work. One way to minimise this is to ensure that the service users you are working with have a mix of different needs.

- **Apply your own knowledge and skills to yourself.** Think of the advice you would give to your service users and/or loved ones about looking after themselves and apply this to yourself.

- **Think about timing.** It may not always be possible to predict or control when you will be completing trauma based work. However, if this is possible, it is worth considering when will be the best time for you to do this type of work. For example, avoid trauma focussed work at the end of a shift,

or at times when there is a shortage of other staff. It is important that following any trauma focussed work, you are able to access support from your staff team if you need it.

- **Peer support.** Your colleagues are perfectly placed to understand the specific difficulties and challenges associated with your work so may be a great source of support.

- **Know your limits.** We all have our own sensitivities and particular topics that are emotionally difficult. It is important to be able to recognise this and say ‘no’ to work if you feel that it isn’t right for you. Remember, it is a strength to know your limits.

Appendix E4: Example from resource pack; resources and information reference sheet

Resources and information

Asking the question

Read, J., Hammersley, P. & Rudegeair, T. (2007). Why, when and how to ask about childhood abuse. *Advances in Psychiatric Treatment, 13*, 101-110.

NHS Confederation (2008). *Implementing national policy on violence and abuse*. London: NHS Confederation. Available from: http://www.nhsconfed.org/~/media/Confederation/Files/Publications/Documents/Implementing%20national%20policy%20on%20violence%20and%20abuse.pdf

Treatment of complex trauma

Herman, J.L. (1992). *Trauma and recovery.* New York: Basic Books.

Courtois, C.A. & Ford, J.D. (2013). *Treatment of complex trauma: A sequenced, relationship-based approach*. London: The Guilford Press.

Mooren, T. & Stofsel, M. (2014). *Diagnosing and treating complex trauma*. Routledge.

Cloitre et al. (2012). The ISTSS Expert Consensus Treatment Guidelines For Complex PTSD In Adults. International Society for Traumatic Stress Studies. Available from: http://www.istss.org/ISTSS_Main/media/Documents/ISTSS-Expert-Concesnsus-Guidelines-for-Complex-PTSD-Updated-060315.pdf

Levitt, J.T. & Cloitre, M. (2005). A clinician's guide to STAIR/MPE: Treatment of PTSD related to childhood abuse. *Cognitive and Behavioral Practice, 12,* 40-52.

Phase one skills

STEPPS Programme Manual.

Linehan, M. (2014). *DBT Skills Training Manual.* New York: Guilford Press.

Appendix E4: Example from resource pack; resources and information reference sheet

Dissociation

Kennerley, H. (1996). Cognitive therapy of dissociative symptoms associated with trauma. *British Journal of Clinical Psychology, 35,* 325-340.

Boon, S., Steele, K. & van der Hart, O. (2011). *Coping with trauma-related dissociation*. New York: W. W. Norton & Company.

Vicarious traumatisation

Sabin-Farrell, R. & Turpin, G. (2003). Vicarious traumatization: Implications for the mental health of health workers? *Clinical Psychology Review, 23,* 449-480.

Website on vicarious trauma: http://www.vicarioustrauma.com/

Self-study module on vicarious traumatization: http://www.headington-institute.org/Default.aspx?tabid=2646

Prevalence of trauma

Radford, L., Corral, S., Bradley, C., Fisher, H., Bassett, C., Howat, N. & Collishaw, S. (2011). *Child Abuse and Neglect in the UK today*. National Society for the Prevention of Cruelty to Children.

Self-help

Lee, D. & James, S. (2012). *Recovering from trauma using compassion focused therapy*. Robinson.

Appendix F: Baseline questionnaire- staff perceived confidence

Questionnaire to rate staff confidence and implementation of phase one trauma techniques with patients.

Instructions

This questionnaire is designed to measure how confident you feel when working with people with a history of trauma. Please take your time to read each question carefully and answer as honestly as you can. Thank you.

	Extremely confident	**Very confident**	**Moderately confident**	**A little confident**	**Not at all confident**
How confident do you feel in your ability to identify patients who may benefit trauma based work?					

	Extremely confident	**Very confident**	**Moderately confident**	**A little confident**	**Not at all confident**
How confident do you feel providing psycho-education about trauma?					

	Extremely confident	**Very confident**	**Moderately confident**	**A little confident**	**Not at all confident**
How confident do you feel in your ability to use any trauma techniques (e.g. grounding, safe place imagery, emotion regulation and discrimination training)?					

Appendix G. Follow up questionnaire. Staff perceived confidence.

Questionnaire to rate staff confidence and implementation of phase one trauma techniques with patients.

Instructions

This questionnaire is designed to measure how confident you feel when working with people with a history of trauma. The questionnaire is also looking at whether your confidence has been affected by the introduction or trauma resources. Please take your time to read each question carefully and answer as honestly as you can. Thank you.

	Extremely confident	Very confident	Moderately confident	A little confident	Not at all confident
If the resources were not available, how confident would you feel in your ability to identify patients who may benefit trauma based work**?**					
If the resources were not available, how confident would you feel providing psycho-education about trauma**?**					
If the resources were not available, how confident would you feel in your ability to use trauma techniques such as grounding, safe place imagery, emotion regulation and discrimination training**?**					

Appendix G. Follow up questionnaire. Staff perceived confidence.

	Extremely confident	Very confident	Moderately confident	A little confident	Not at all confident
How confident do you feel in your ability to identify patients who may benefit trauma based work**?**					
How confident do you feel providing psycho-education about trauma**?**					
How confident do you feel in your ability to use any trauma techniques (e.g. grounding, safe place imagery, emotion regulation and discrimination training)?					

Appendix G. Follow up questionnaire. Staff perceived confidence.

Questionnaire to rate the usefulness of trauma therapy skills resources.

Instructions

In September 2015 you were introduced to a range of resources, designed to facilitate your use of trauma therapy skills with service users.

This questionnaire is designed to measure how often you have used these resources and how helpful you have found them. Please take your time to read each question carefully and answer as honestly as you can. Thank you.

	Yes	**No**
1. Since September, when the resources were introduced, have you had the opportunity to use trauma based skills with a patient (e.g. psycho-education, grounding techniques, safe place imagery and emotion regulation)?	☐	☐

2. If yes, how often did you refer to the trauma therapy skills resources?

Every time	**Some of the time**	**About half the time**	**Rarely**	**Never**
☐	☐	☐	☐	☐

3. Please tick the resources you have used….

a) Information about what trauma is ☐

b) Information about treatment for trauma ☐

c) Grounding techniques ☐

d) Relaxation techniques ☐

e) Further information for staff ☐

f) Other (please state) ☐

……..

Appendix G. Follow up questionnaire. Staff perceived confidence.

4a. Please indicate how useful you have found these resources

	Not at all useful	Slightly useful	Somewhat useful	Very useful	Extremely useful	N/A
a) Information about what trauma is						
b) Information about treatment for trauma						
c) Grounding techniques						
d) Relaxation techniques						
e) Further information for staff						
f) Other (please state) …… …..						

4b) Please use the space below to explain your answers….
…… …… …… …… ……..

5. Thinking back to before the resources were introduced, has the amount of trauma based work you've provided changed?

I have done less trauma based work since September	**I have done about the same amount of trauma based work since September compared to before this date.**	**I have done more trauma based work since September.**
☐	☐	☐

Appendix G. Follow up questionnaire. Staff perceived confidence.

6) If there has been a change in the amount of trauma based work you have completed with patients, why do you think this is (please tick all that apply).

a) Additional training ☐

b) More or fewer appropriate patients ☐

c) Having access to the trauma skills resources ☐

d) Having less or more access to appropriate supervision. ☐

e) Other (please state)……

Appendix H. Instructions for authors Journal of Intellectual Disability Research

Structure

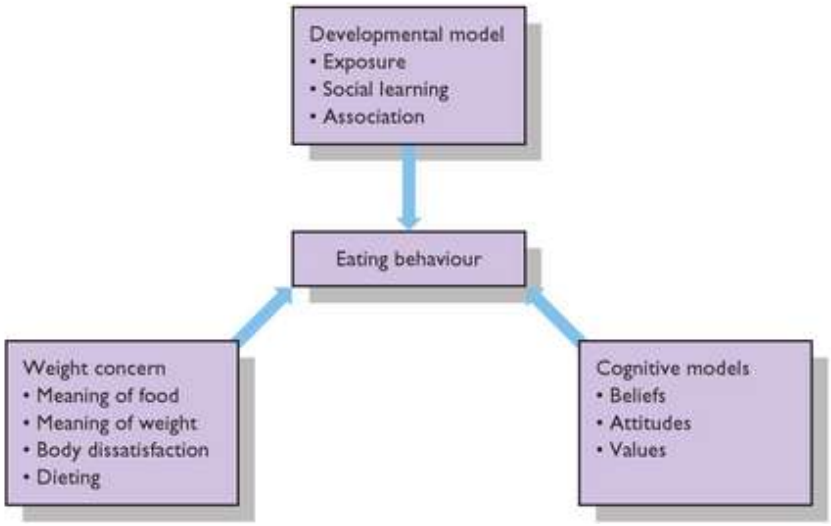
All manuscripts submitted to *The Journal of Intellectual Disability Research* should include: Title, Keywords, structured Abstract, Main Text (divided by appropriate sub headings) and References.

Title Page: Please remember that **peer-review is double-blind**, so that neither authors nor reviewers know each others' identity. Therefore, **no identifying details of the authors or their institutions must appear in the submitted manuscript; author details should be entered as part of the online submission process**. However, a 'Title Page' must be submitted as part of the submission process as a 'Supplementary File Not for Review'. This should contain the title of the paper, names and qualifications of all authors, their affiliations and full mailing address, including e-mail addresses and fax and telephone numbers.

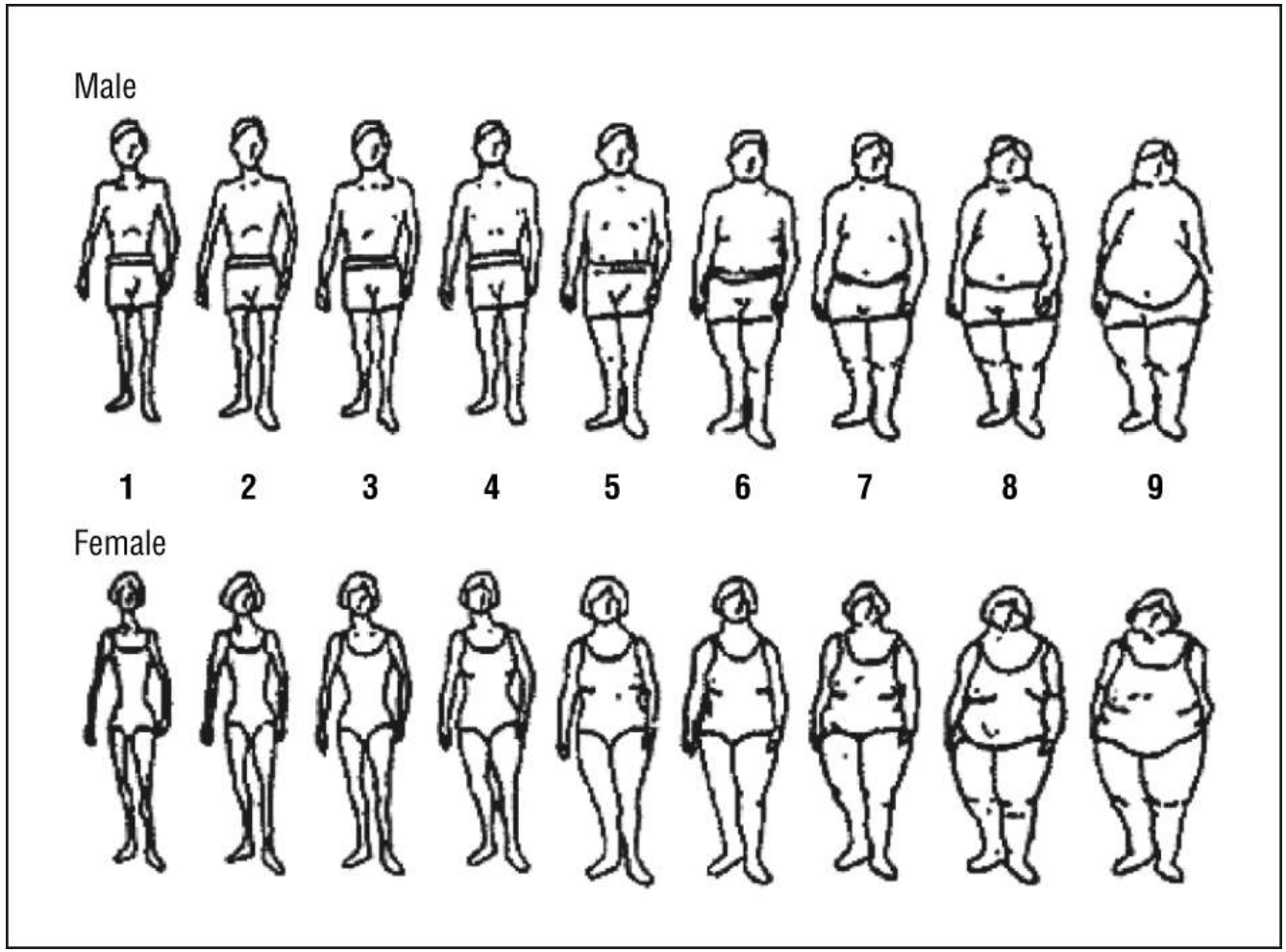
Keywords: The author should also provide up to six keywords to aid indexing. Please think carefully about the keywords you choose as this will impact on the likelihood of your article being located during literature searches (https://authorservices.wiley.com/bauthor/seo.asp).

Abstracts: For full and brief reports, and reviews, a structured summary should be included at the beginning of each article, incorporating the following headings: Background, Method, Results, and Conclusions. These should outline the questions investigated, the design, essential findings, and the main conclusions of the study.

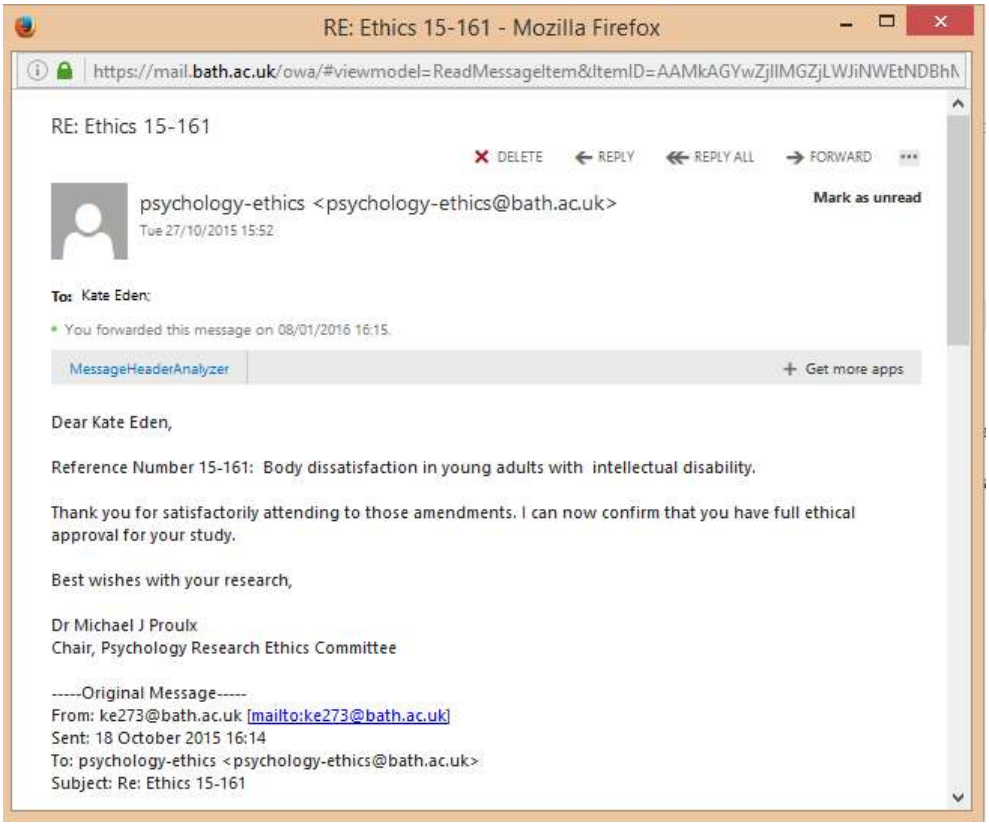
Appendix I. Developmental, Cognitive and Weight concern model of eating behaviour.



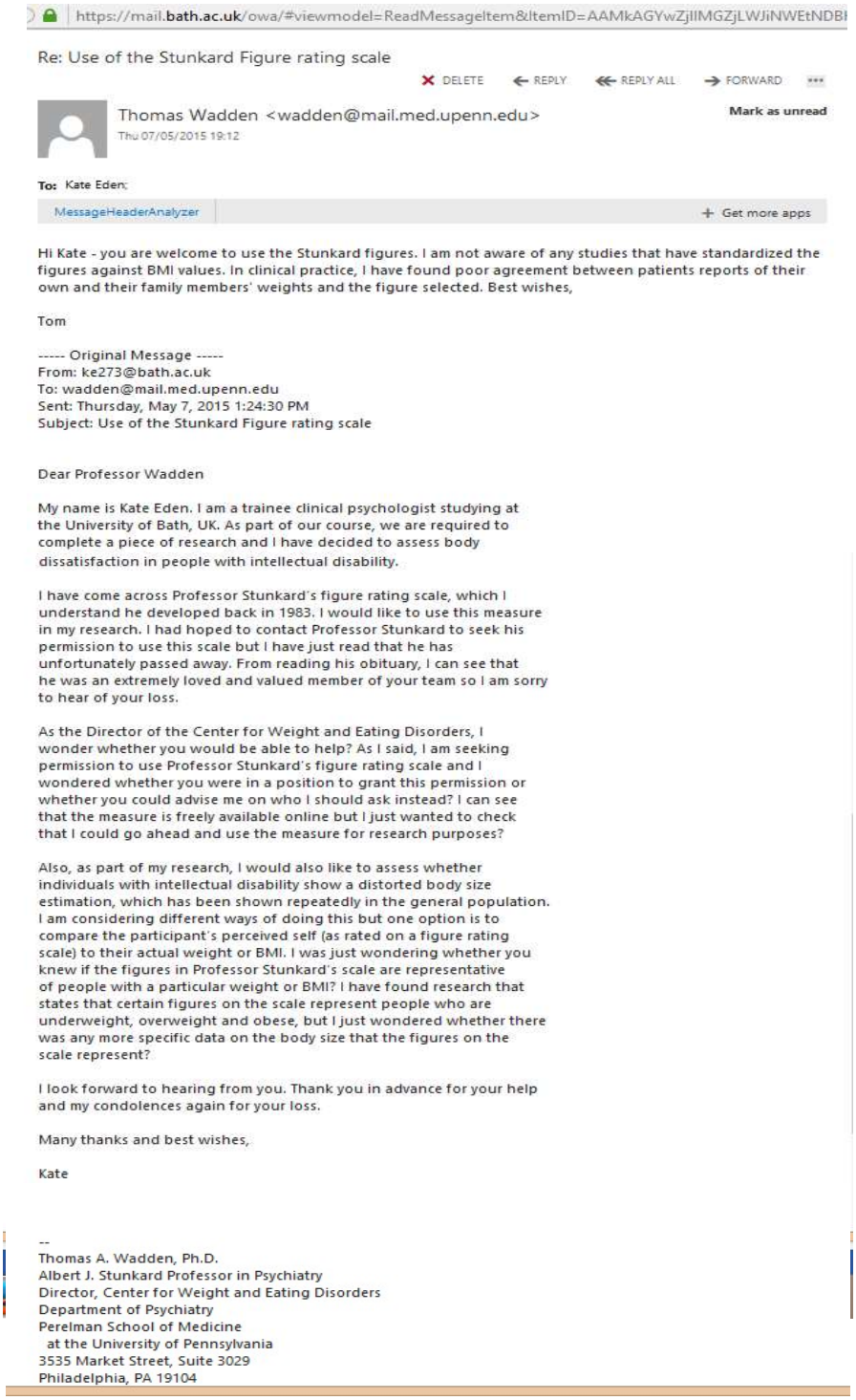
Appendix J. Stunkard Figure Rating Scale



Appendix K. Confirmation of ethical approval for main research project



Appendix L. Permission to use the Stunkard Figure Rating Scale



https://mail.bath.ac.uk/owa/#viewmodel=ReadMessageItem&ItemID=AAMkAGYwZjlMGZjLWJiNWEtNDBl

Re: Use of the Stunkard Figure rating scale

DELETE REPLY REPLY ALL FORWARD

Thomas Wadden <wadden@mail.med.upenn.edu>
Thu 07/05/2015 19:12

Mark as unread

To: Kate Eden;

MessageHeaderAnalyzer + Get more apps

Hi Kate - you are welcome to use the Stunkard figures. I am not aware of any studies that have standardized the figures against BMI values. In clinical practice, I have found poor agreement between patients reports of their own and their family members' weights and the figure selected. Best wishes,

Tom

----- Original Message -----
From: ke273@bath.ac.uk
To: wadden@mail.med.upenn.edu
Sent: Thursday, May 7, 2015 1:24:30 PM
Subject: Use of the Stunkard Figure rating scale

Dear Professor Wadden

My name is Kate Eden. I am a trainee clinical psychologist studying at the University of Bath, UK. As part of our course, we are required to complete a piece of research and I have decided to assess body dissatisfaction in people with intellectual disability.

I have come across Professor Stunkard's figure rating scale, which I understand he developed back in 1983. I would like to use this measure in my research. I had hoped to contact Professor Stunkard to seek his permission to use this scale but I have just read that he has unfortunately passed away. From reading his obituary, I can see that he was an extremely loved and valued member of your team so I am sorry to hear of your loss.

As the Director of the Center for Weight and Eating Disorders, I wonder whether you would be able to help? As I said, I am seeking permission to use Professor Stunkard's figure rating scale and I wondered whether you were in a position to grant this permission or whether you could advise me on who I should ask instead? I can see that the measure is freely available online but I just wanted to check that I could go ahead and use the measure for research purposes?

Also, as part of my research, I would also like to assess whether individuals with intellectual disability show a distorted body size estimation, which has been shown repeatedly in the general population. I am considering different ways of doing this but one option is to compare the participant's perceived self (as rated on a figure rating scale) to their actual weight or BMI. I was just wondering whether you knew if the figures in Professor Stunkard's scale are representative of people with a particular weight or BMI? I have found research that states that certain figures on the scale represent people who are underweight, overweight and obese, but I just wondered whether there was any more specific data on the body size that the figures on the scale represent?

I look forward to hearing from you. Thank you in advance for your help and my condolences again for your loss.

Many thanks and best wishes,

Kate

--
Thomas A. Wadden, Ph.D.
Albert J. Stunkard Professor in Psychiatry
Director, Center for Weight and Eating Disorders
Department of Psychiatry
Perelman School of Medicine
at the University of Pennsylvania
3535 Market Street, Suite 3029
Philadelphia, PA 19104

Participant ID:

Information sheet comprehension checklist

	Understands? Yes	No
What is the study about? • Mentions how he/she thinks about their body	☐	☐
What will you be asked to do? • Measure weight • Answer questions	☐	☐
Are you allowed to say no to taking part?	☐	☐
Can you change your mind and stop taking part if you want to?	☐	☐
Do you have to answer any questions that you don't want to?	☐	☐
Will your information be kept private so that other people don't know your answers?	☐	☐
Will we write about our findings in a journal?	☐	☐
All answers correct?	☐	☐

_____ _____

Researcher's signature Date

Participant ID:

Body dissatisfaction in people with intellectual disability

Qualitative questions

1. How do you feel about how you look?

2. Is there anything you would like to change about your body?

3. Why would you want to change that about your body?

4. What do other people think about how you look?

5. Some people want to change how they look. Why might some people want to change how they look?

6. Which of these best describes you; underweight, overweight or around the middle?

☐ Underweight ☐ Around the middle ☐ Overweight